

**QUALITY OF LIFE  
FOR PATIENTS DIAGNOSED WITH SCHIZOPHRENIA  
LIVING IN THE COMMUNITY  
IN GREECE**

**PANAGIOTA DIMITRIOU  
(RN, MSc, MBA)**

Thesis submitted in partial fulfilment for the Degree of Philosophy  
undertaken in the Faculty of Health and Community Studies,  
School of Nursing and Midwifery  
DeMontfort University,  
Leicester, UK

**SEPTEMBER 2007**

**BEST COPY  
AVAILABLE**

**TEXT IN ORIGINAL  
IS CLOSE TO THE  
EDGE OF THE  
PAGE**

## **ABSTRACT**

The meaning of quality of life as experienced by patients diagnosed with schizophrenia living in the community in Greece has never been a topic of study, either in the Greek or in the international mental health literature. The meaning of “quality of life” in relation to a person diagnosed with schizophrenia is explored through the relevant literature. Discussions and arguments on the methodological approaches, and the research methods used by researchers are provided in the literature review chapter.

The study took place in two phases. Mixed research methods were employed in order to answer the research question of this study. Eight informants were interviewed in the first phase and five life domains were defined as contributing to the informants' quality of life: work and money, family, social functioning, psychological functioning and health. These five domains guided the choice of the quantitative tool in order further explore the research question of the study and to measure the quality of life of patients diagnosed with schizophrenia. The Greek version of the Subjective Quality of Life Profile was used in 100 people diagnosed with schizophrenia living in the community in Greece, and the results showed that the majority of them experienced overall satisfaction and that they were expecting changes for the better to come in the future. This study contributes towards the expansion of knowledge in the mental health area and is expected to be the initiative for further research, since it is the first study to examine the meaning of quality of life of people diagnosed with schizophrenia living in the community in Greece.

## **DEDICATION**

**This work is dedicated to my wonderful 15 year old son Billy, who has provided endless encouragement and support throughout my studies. Billy lived the real meaning of a PhD study-journey and he enthusiastically looked forward to the completion of this work. I strongly believe that this experience will inspire him to achieve his own future career goals and ambitions.**



## **ACKNOWLEDGEMENTS**

I would like to thank the people who helped me through out this work. The order does not represent the significance of the role which they played towards the completion of the current study.

I am grateful to my supervisor Professor Denis Anthony for his endless help, support, encouragement, and patience through-out this study and especially for his valuable help in making statistics an understandable piece of work.

I am very much grateful to my husband Konstantinos for his support and understanding during the time this work took place.

Many thanks go to the nurses of the mental health community centre where this study took place and especially Mrs Papageorgiou and Mrs Zika who helped me during the two phases of the study. Without their support the data collection would have been a real burden.

I would like to thank Mr Ploubidis, the Director of the mental health community centre for his approval to conduct the study at his centre and for his valuable help with during the first phase of the study.

Special thanks go to the participants of the current study for their participation in both phases of the study and for their willingness to share their personal experiences with me.

Very special thanks go to my father and sisters who emotionally supported me to accomplish this work.

Last but not least, I would like to thank Sue Dyson for her invaluable help in reviewing and correcting this Thesis.

## **CONTENTS**

	PAGE
TITLE PAGE.....	i
ABSTRACT.....	ii
DEDICATION.....	iii
ACKNOWLEDGEMENTS.....	iv
CONTENTS.....	v
LIST OF TABLES.....	ix
LIST OF FIGURES.....	xi
<b>CHAPTER ONE</b>	
INTRODUCTION	
1.1 Background.....	1
1.2 Research question.....	2
1.3 Outline of the Thesis.....	2
<b>CHAPTER TWO</b>	
LITERATURE REVIEW	
2.1 Philosophical and Sociological aspects of quality of life.....	5
2.2 Quality of life in the health care context.....	10
2.3 Schizophrenia and quality of life.....	11
2.3.1 The illness of schizophrenia.....	11
2.3.2 Epidemiology of schizophrenia.....	14
2.3.3 Quality of life and schizophrenia.....	15
2.3.4 Sociodemographic determinants.....	17
2.3.5 Psychopathology.....	18
2.3.6 Treatment.....	19
2.3.7 Stigma.....	20
2.3.8 Cross-cultural differences.....	22
2.3.9 Place of treatment .....	25
2.4 Measurement of quality of life.....	28
2.4.1 Social Indicators of Quality of Life.....	28
2.4.2 Objective social indicators .....	29
2.4.3 Subjective indicators of quality of life.....	31

2.5 Community mental health care in Greece .....	33
2.5.1 The function of the community mental health centre where the study took place .....	36
<b>CHAPTER THREE</b>	
<b>RESEARCH METHODOLOGY AND METHODS .</b>	39
3.1 Introduction.....	39
3.2 Theoretical Framework .....	39
3.2.1 Paradigms and Nursing Research .....	39
3.2.2 Qualitative research method .....	43
3.2.3 Phenomenology in the Nursing Science .....	49
3.2.4 Quantitative research method ..	51
3.3 Combining qualitative and quantitative methods: mixed methods .....	55
3.4 Paradigms, nursing theories, and nursing research in Greece.....	58
3.5 The current study... ..	59
3.5.1 Phase one. ....	61
3.5.2 Phase two.....	63
3.5.3 Ethical considerations .....	64
3.5.5 Sampling.....	66
<b>CHAPTER FOUR</b>	
<b>METHODOLOGY PHASE ONE</b>	
4.1 Process of Phase One .....	69
4.1.1 Data collection .....	69
4.1.2 Participants' characteristics.....	71
4.1.3 Timing of the interviews .....	72
4.1.4 Validity .....	73
4.1.5 The interviews .....	73
4.1.6 Analysis of the Qualitative Data .....	76
<b>CHAPTER FIVE</b>	
<b>QUALITATIVE FINDINGS AND DISCUSSION PHASE ONE</b>	
5.1 Findings and Discussion .....	79
5.1.1 General Findings .....	80
5.1.2 Work and money .....	82
5.1.3 Family .....	86

5.1.4 Social Functioning, Health, and Psychological Functioning .....	89
<b>CHAPTER SIX</b>	
<b>METHODOLOGY PHASE TWO</b>	
6.1 Process of Phase Two.....	105
6.1.1 Choosing the appropriate quality of life questionnaire.....	105
6.1.2 Lehman Quality of Life Interview .....	107
6.1.3 The Lancashire Quality of Life Profile .....	108
6.1.4 Medical Outcome Study 36-item Short Form .....	109
6.1.5 The Subjective Quality of Life Profile .....	112
6.1.6 Appropriateness of the reviewed quality of life instruments.....	116
<b>CHAPTER SEVEN</b>	
<b>ANALYSIS OF DATA AND FINDINGS PHASE TWO</b>	
7.1 Analysis of the quantitative data .....	121
7.1.1 Demographic characteristics.....	121
7.2 Descriptive analysis.....	126
7.3 Factor analysis .....	132
7.4 General linear model: Analysis of variance .....	133
7.6 Conclusion .....	135
<b>CHAPTER EIGHT</b>	
<b>DISCUSSION PHASE TWO</b>	
8.1 Discussion of Findings .....	137
<b>CHAPTER NINE</b>	
<b>CONCLUSIONS</b>	
8.1 Overall conclusions of the study .....	150
8.2 Implications of the study .....	152
8.3 Limitations of the study .....	154
8.4 Recommendations for further research .....	156
<b>CHAPTER TEN</b>	
<b>INTERVIEWS</b>	
10.1 Interview with Alexander .....	157
10.2 Interview with Maria .....	161
10.3 Interview with Michael .....	165
10.4 Interview with Tasos.....	170

10.5 Interview with Anna – Maria..... 177

10.6 Interview with Martha ..... 184

10.7 Interview with Soula..... 188

10.8 Interview with Vasiliki..... 193

**REFERENCES..... 198**

**APPENDIX A (Consent form and Information sheet)..... 237**

**APPENDIX B (Detailed statistical results)..... 239**

**APPENDIX C (The questionnaire)..... 259**

## **LIST OF TABLES**

Table 1: Assumptions of Positivist and Naturalistic Paradigms.....	42
Table 2: Interview topic guide.....	70
Table 3: Participant's Characteristics.....	72
Table 4: Application of Phenomenological characteristics.....	74
Table 5: Gender and First Names of the participants.....	80
Table 6: Raw data for quality of life indicators.....	97
Table 7: Categorization into themes.....	99
Table 8: Clarification of the concept Quality of Life.....	101
Table 9: Quality of life concept clarification.....	104
Table 10: SQLP Population Applications.....	115
Table 11a: Comparison of the reviewed tools (a).....	116
Table 11b: Comparison of the reviewed tools (b).....	117
Table 12: Life domain per Question.....	125
Table 13: Mean Value per question item.....	127
Table 14: Categorisation of the core questions.....	129
Table 15: Variables loaded on the factors.....	133
Table 16: Correlations.....	134
Table 17: Scores of quality of life domains.....	138
Table 18: Factor analysis for satisfaction of core questions.....	239
Table 19: Component Matrix (a).....	240
Table 20: Factor analysis perceived importance of core questions.....	241
Table 21: Component Matrix (a) .....	242

Table 22: Factor analysis expectation of change of core questions.....	243
Table 23: Component Matrix(a).....	244
Table 24: General linear model for satisfaction.....	245
Table 25: General linear model for perceived importance.....	247
Table 26: General linear model for expectation of change.....	249
Table 27: General linear model of disease specific questions.....	251
Table 28: General linear model for perceived importance of disease specific questions.....	253
Table 29: General linear model for expectation of change of disease specific questions.....	255
Table 30: General linear model for expectation of change of disease specific questions. Tests of Between-Subjects Effects.....	257

**LIST OF FIGURES**

Figure 1: Age profile..... 122

Figure 2: Years of sickness..... 123

Figure 3: Level of education..... 124

Figure 4: Mean satisfaction..... 130

Figure 5: Mean perceived importance..... 131

Figure 6: Mean expectation of change..... 132



## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.1 Background**

My interest in the quality of life for the patients diagnosed with schizophrenia living in the community in Greece, began while I was taking my psychiatric nursing specialization in a large Greek community mental health centre. It was at that time that I came closer to those who lived in a Greek community area and at the same time were living with the experience of being diagnosed with schizophrenia. Having uncovered the multidimensionality of the concept of quality of life in my research proposal during my Master's Degree, I started wondering whether the people diagnosed with schizophrenia would describe the domains of their lives which may contribute to quality of life, in the same way as is considered in the relevant literature. My interest became even stronger when, after searching the Greek literature, I realized that there was a notable absence of studies that consider the quality of life for Greek outpatients. No one study had ever identified the meaning of quality of life for this specific population, nor had any study measured it. I viewed this lack of relevant Greek studies as a "patient-focused discrimination" for patients diagnosed with schizophrenia and I decided to explore and measure their quality of life. The current study became an interesting personal journey while moving from one step to the next. This journey is described in the chapters of this thesis.

## **1.2 Research Question**

The research question guiding the current study is: “**what is the meaning of quality of life for the patients diagnosed with schizophrenia living in the community in Greece?**” During the first phase of the study, the quality of life domains were identified and the research question was further expanded during the second phase of the study, while measuring the quality of life for the patients diagnosed with schizophrenia living in the community in Greece.

## **1.3 Outline of the Thesis**

Following this introductory Chapter, relevant literature is reviewed in **Chapter Two** in order to explore the concept of quality of life and to identify previous work on quality of life for outpatients diagnosed with schizophrenia. There is a generally agreed difficulty regarding a definition of quality of life, due to its subjective nature. In Chapter two the concept of quality of life is examined through its objective and subjective indicators and relevant studies from the area of mental health as well as from other medical areas. The literature review informed the choice of research methodology and the research methods, subsequently utilised in this study.

In **Chapter Three** the distinction between methodology and method is discussed. Methodology is the theoretical thinking or framework governing the study and the design of the method, while method refers to the procedures and instruments, which are to be applied (Dickoff et al, 1992). Two main nursing theoretical frameworks are discussed: the positivist and the naturalistic. The current study was guided by the naturalistic framework since

the researcher's aim was to explore the phenomenon of quality of life for the outpatients diagnosed with schizophrenia. The naturalistic framework guided the researcher to choose mixed-methods combining qualitative and quantitative approaches. The strengths and weaknesses of the research methods are discussed and previous studies employing either quantitative or qualitative or mixed methods are reviewed. The chapter ends with an overall description of the two phases of the current study. In **Chapter Four** the first phase is described. Eight informants were interviewed and asked to express their experience of quality of life as they were living it. The process of the interviews, data collection, and data analysis are presented in this chapter. The findings are discussed in relation to previous studies in **Chapter Five**. The life domains contributing to quality of life as experienced by the eight informants, guided the researcher to further expand the research question by employing quantitative method. The most appropriate tools are reviewed in **Chapter Six**. The selection of the Subjective Quality of Life Profile (Gerin et al, 1992) for the second phase of the current study and the fulfilment of the requirements set by the researcher are also discussed. The methodology for the second phase is described in **Chapter Seven** in terms of data analysis, and findings. The findings are discussed with reference to relevant studies in **Chapter Eight**. The overall conclusions of the current study are provided in **Chapter Nine** in order to make clear how the aim of this research study have been achieved throughout out this knowledge and experience gaining journey. In Chapter nine, the limitations of the study, as well as the implications of the results to knowledge contribution and mental health practice are also discussed. In the same Chapter recommendations for further research are

made in order to encourage nurse researchers to further explore the lived experiences of patients diagnosed with schizophrenia on quality of life.

The detailed interviews with the eight informants are provided in **Chapter Ten**. Finally, **APPENDIX A** provides the consent form and the information sheet, **APPENDIX B** includes the tables of the detailed statistical results after the analysis of the quantitative data, and **APPENDIX C** provides the tool used in the second phase of the study: the Subjective Quality of Life Profile.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Philosophical and sociological aspects of quality of life**

The concept of "quality of life" seems to remain difficult to define. A remarkable number of studies (Flanagan, 1982; Larson, 1978; McCall, 1975; Liu, 1974) defining the concept of quality of life appeared in the 1970s and 80s, when social scientists and philosophers focused their interest on quality of life. Depending on the investigator's interest, some definitions focus on a single domain of quality of life such as health or happiness or life satisfaction (Flanagan, 1982; Burkhardt and Nagai-Jacobson, 1985), which usually are equated with quality of life, while a number of different domains are examined as aspects of quality of life such as: income, environment, psychosocial well-being (Harwood, 1976; Larson, 1978). In other words, quality of life is approached as a unidimensional or as a multidimensional phenomenon. However, it is not an easy task to isolate one or another domain, which may influence a person's quality of life. Aaronson (1990) suggested that it is more sensible to examine a number of relevant factors of quality of life, in order to define and to measure the concept.

Liu (1974) in his sociological approach to the meaning of quality of life suggested that quality of life varies across place, time, and persons themselves. He defined quality of life as the "output" of the two "input" factors: physical and spiritual. The physical factors include quantifiable goods, services, and material wealth, while the spiritual factors concern all

psychological, sociological, and anthropological aspects such as: love, community belongingness, esteem, and affection. In other words, these factors could be objective and subjective domains of quality of life. The objective domains represent the person's standards of living, while the subjective ones represent the way in which the person perceives life (Romney and Evans, 1996).

The philosopher McCall (1975) viewed quality of life in relation to a person's happiness. He stated that quality of life depends on the degree a person's life meets the "general happiness requirements", which refer to the necessary conditions of anyone's happiness. Going further, McCall suggested that the general happiness requirements can be provided by satisfying the human wants and desires, and the human needs. Human wants and desires reflect the person's view of life and refer to the subjective way of assessing life. In contrast, human needs may refer to the objective assessment of one's life.

The degree of satisfaction based on human wants and desires is correlated to the expectations one has throughout his/her life. It seems that this phenomenon had long since been under consideration, when according to the Epicureans in ancient Greece, the degree of satisfaction depended on the degree of attainment as well as the expectations one has throughout life. In this way the emphasis is on the endless process of wanting or desiring things or situations during life (Aristotle, 1941).

On the other hand, human needs can be specific and satisfied at some point in a person's life. This notion is supported by looking at Maslow's

hierarchy of needs according to which the higher needs are met only after the basic ones have been met. Maslow's hierarchy of needs is revised below in an attempt to make clear the way individuals experience satisfaction while meeting their needs throughout their life (Hanley and Abell, 2002):

- Physiological needs. Refer to the basic human needs required to sustain life, which include food, water, sleep, clothing, and shelter. If these needs are not met, dominate the individual's behaviour.
- Safety or security needs. Refer to the needs for protection from harm and for a secure and safe life.
- Belongingness needs. Concern the need for love and affection. They are divided between the passive need to be loved and the active need to love others.
- Esteem needs. The need for a stable and usually high evaluation of one's self. These are also divided into a need for the respect or esteem of others and for self-esteem or self-respect.
- Self-actualisation needs. In the highest category of needs, they refer to matureness of a person as well as to emotional balance and self-acceptance in challenging situations.

It can be noted that according to Maslow's hierarchy of needs the evaluation of quality of life can be based on objective criteria for all people at any time and place. However, the notion of quality of life might be different from one society to another, since some of these needs may be culturally determined. McCall (1975) suggested that according to Maslow's theory, the level of quality of life for some societies might be low and for other societies

high, depending on the available resources and the level at which the needs are met. In this way, he suggested that comparisons and measurement of the quality of life in societies at different places and time will be possible. Maslow's theory could be a valuable tool in drawing up a list of needs, considering this as the first step in laying down a set of objective criteria for quality of life.

Flanagan (1978) conducted a national survey in several regions of the United States in an attempt to extract the critical elements of quality of life for Americans. Through an inductive process, 15 categories of quality of life components arose listed in five headings: physical and material well being; relations with other people; social, community, and civic activities; personal development and fulfilment; and recreation. During the second stage of the survey, people were asked what things were interfering with their needs and wants. Most of the participants (80%) said that the 15 categories of quality of life components were representing their needs and wants, which were generally met. It is obvious that if the components of quality of life can be revealed, satisfaction of the related needs and wants can be measured. This notion refers to the objective criteria on which the evaluation of quality of life can be based.

Harwood (1976) in an attempt to ascertain conceptualisations of quality of life in the public mind reviewed three models: ascriptive model, testimony model, and importance model. The ascriptive model includes quality of life components as they are proposed by the Economic Council of Canada and are divided into political dimensions, social dimensions, and economical dimensions (Harwood, 1976). The political group of quality of life components



includes individual rights, legal rights, political and participatory rights and responsibilities, and national identity. The social dimensions of quality of life are: health (physical and mental), command over knowledge and skills, natural environment, and man-made environment. Finally, the economic dimensions include goods and services, efficiency, and outputs (p.472-473).

The testimonial model refers to the subjective, person-centred model of quality of life. Andrews and Withey (1976) developed a model on subjective quality of life factors and it has two dimensions: values (achieving success, safety, and fun), and domains (job, family life). The authors concluded that the final product of all possible interactions between values and domains is the individual's perceived quality of life.

According to the Importance Model, the quality of life components are put in an order of hierarchy depending on the individual's perception of quality of life (Harwood, 1976). Harwood (1976) suggested that this model could provide an indirect way of measuring quality of life from the individual's perspective, but it is the author's opinion that the importance of the individual's perspective should be placed on the components themselves and not in the order in which they are put. An individual may place a particular component on a particular order but in reality this component is still central to their experience. This is one of the key problems when using a model dependent in an orderly system.

## **2.2 Quality of life in the health care context**

The term quality of life was first met in a medical journal in 1966, when Elkinton published an editorial titled: "Medicine and the quality of life", in the Annals of Internal Medicine (cited by Whitty et al, 2004, p.805).

The search of the relevant literature reveals that a great number of medical researchers have shown their interest in this topic, since research findings show that health is the major and the most important aspect of quality of life (Padilla et al, 1990; Laborde and Powers, 1980; Flanagan, 1982).

Traditionally, medicine is concerned with people's well being and the interventions made by the physicians are focused on the balance between iatrogenic harm and therapeutic benefit (Cella, 1992). Under this point of view, quality of life should be assessed as an end point in treatment studies in several medical specialities. Najman and Levine (1981) in their review on the impact of medical care and technologies on the quality of life agree, that health care ought to be assessed in terms of its impact on quality of life. They suggested that the outcome of medical care is to relieve symptoms, reduce pain, improve mental health or restore functioning. Similarly, many medical researchers relate their interest in the quality of life to the outcomes of the medical treatment. In cancer research, DeHaes & Knippenberg (1985) reviewed relevant literature on the quality of life of cancer patients and reported that the intention of quality of life studies is: to reveal the reactions of cancer patients to the treatment and the interrelations of different reactions and the quality of life, to give insight to the impact of cancer therapies on the quality of life, and to enhance supportive care for cancer patients based on the results of the quality of life studies (DeHaes & Knippenberg, 1985).

According to Aaronson (1990), the purposes of assessing the quality of life of oncology patients are: to describe the extent of functional and psychosocial problems facing cancer patients, to establish norms for psychosocial morbidity among specific patient groups, to monitor the quality of care in order to improve.

## **2.3 Schizophrenia and quality of life**

### **2.3.1 The Illness of Schizophrenia**

Schizophrenia remains the major mental illness of our time. However, the aetiology of schizophrenia remains unclear. Risk factors such as genetic, perinatal complications and winter births have been identified by Carpenter and Buchanan (1995), while other authors have studied obstetric complications, urban/rural birth and family environment, and stress as well as delayed childhood development as main causative factors for schizophrenia. (Hultman, 1999; Pedersen, 2001).

Coffey (1998), in a historical review stated that the first description of schizophrenia was given by Pinel, in 1801. Pinel used the term “démence” to describe the mental deterioration of chronically ill hospitalised patients. In 1852, Morel used the term *démence précoce* to describe young patients with dementia and he used the course of illness as the classification basis for it. In 1893 Kraepelin used the term *dementia praecox* and emphasised the aetiology and the outcome of it (Beer, 2002). In 1911, Bleuler gave the name of schizophrenia to the condition characterised by disturbances of thought, perception and a blunting of affect (Coffey, 1998). The main symptoms of schizophrenia were described by Schneider, a German psychiatrist as

namely, auditory hallucinations, passivity experience, and delusional thinking (Coffey, 1998). In contemporary literature, the classification of schizophrenia is based on two main texts which classify and describe mental illnesses, including schizophrenia. These are the International Classification of Diseases-10 (ICD-10, 1993), which represents the European description of mental illnesses and the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV-TR, 2000), which represents the American description of mental illnesses.

According to ICD-10 (1993), the symptoms of schizophrenia are divided into the following groups:

- a. thought echo, thought insertion or withdrawal, and thought broadcasting;
- b. delusions of control, influence, or passivity, clearly referred to body or limb movements or specific thoughts, actions, or sensations; delusional perception;
- c. hallucinatory voices giving a running commentary on the patient's behaviour, or discussing the patient among themselves, or other types of hallucinatory voices coming from some part of the body;
- d. persistent delusions of other kinds that are culturally inappropriate and completely impossible, such as religious or political identity, or superhuman powers and abilities;
- e. persistent hallucinations in any modality, when accompanied either with fleeting or half-formed delusions without clear

**affective content, or by persistent over-valued ideas, or when occurring every day for weeks or months;**

- f. breaks or interpolations in the train of thought, resulting in incoherence or irrelevant speech, or neologisms;**
- g. catatonic behaviour, such as excitement, posturing or waxy flexibility, negativism, and stupor;**
- h. “negative” symptoms such as apathy, paucity of speech, and blunting or incongruity of emotional responses, usually resulting in social withdrawal and lowering of social performance (it must be clear that these are not due to depression or to neuroleptic medication);**
- i. a significant and consistent change in the overall quality of some aspects of personal behaviour, manifest as loss of interest, aimlessness, idleness, a self-absorbed attitude, and social withdrawal.**

**The ICD-10 suggests that the required aetiology for the diagnosis of schizophrenia is at least one from the groups a to group d, or at least two from the groups e to h, present for a one month period or more.**

**According to DSM-IV-TR (2000), the characteristic symptoms of schizophrenia are divided in two main criteria:**

- a. positive symptoms: delusions, hallucinations, disorganised speech (e.g. frequent derailment or incoherence), grossly disorganised or catatonic behaviour; negative symptoms: affective flattening, alogia, or avolition;**

- b. social/occupational dysfunction such as work, interpersonal relations, or self-care are remarkably below the level achieved prior to onset;

The DSM-IV requires continuous symptoms to persist for at least 6 months, including at least one month of symptoms under criterion a or only negative symptoms or two or more symptoms under criterion a present in an attenuated form. Schizoaffective disorder, mood disorder, and substance/medical condition are excluded from the diagnostic criteria. Despite their slight differences concerning the time frame between the onset and the diagnosis of schizophrenia, the two classification texts provide an international tool for use by all mental health professionals in terms of diagnostic guidelines and research criteria.

### 2.3.2 Epidemiology of schizophrenia

Despite the difficulties concerning the definition and the aetiology of schizophrenia, it is globally agreed that the incidence of this mental illness usually refers to 1% of the population (Awad et al, 1997). The onset of schizophrenia is typically in late adolescence or early adulthood (McGrath,2006), with 90% of males and 70% of females becoming ill before the age of 30 years (Revicki et al, 1999; Awad et al, 1997). The incidence of schizophrenia is significantly higher in males than in females with the male/female ratio = 1.4 (McGrath,2006; McGrath et al, 2004; Aleman et al, 2003). The influence of onset and age on the quality of life of those who suffer from schizophrenia, have been studied by several authors (Patterson et al, 1997; Wanner et al, 1997; Corrigan and Buican, 1995). Most researchers

report little effect of age and gender on quality of life (Browne et al, 1996; Vandiver, 1998), or to favour women. Skantze et al (1992) reported that that quality of life is independent of marital status while Corrigan and Buican (1995) found a strong association between improved quality of life and marital status.

The treatment of schizophrenia since the 1950s has mostly been anti-psychotic medication, which leads to relief of symptoms in 70% to 80% of patients and is also associated with variable side-effects (Revicki et al, 1999).

### 2.3.3. Quality of life and Schizophrenia

Schizophrenia, like any other illness, has an impact on the patient's quality of life. Patients diagnosed with schizophrenia, are able to assess their quality of life as well as the general population (Skantze et al, 1992).

Following the movement towards the deinstitutionalisation of mentally ill people in the 1980s, the application of the concept of quality of life in the community mental health field was introduced by Lehman et al (1982) who explored the quality of life of chronically mentally ill patients in community settings in Los Angeles (Lehman et al, 1982) and in Baltimore (Lehman et al, 1986). Lehman et al (1982) defined quality of life in community mental health in terms of time, community integration, financial status, and safety.

Referring to the patients diagnosed with schizophrenia living in the community, the presence of specific symptoms of schizophrenia, the age of the client, the treatment, as well as the place of treatment, the educational level and the financial status of the client, have been examined in association

with the impact they have on the quality of life of patients' diagnosed with schizophrenia.

Most of the studies on quality of life incorporate a social perspective examining how quality of life aspects such as housing, health, finances, and social relationships interact with mental health (Kuyken et al, 1994; Kreiger and Fee, 1994). Malm et al (1981) reported that patients diagnosed with schizophrenia living in the community experienced dissatisfaction with the areas of education, leisure and relationships. Dissatisfaction with life domains such as safety, education, relationships, leisure and global well being are also shown in several studies to impact negatively on mentally ill patients (Rodner-Wanner et al, 1997; Huxley and Warner, 1992). Similarly, in Skantze's et al study (1992) patients diagnosed with schizophrenia were dissatisfied with regard to work and activities, health and care, leisure, contact with others, dependence and religion.

More recently, Gee et al (2003) used a grounded theory approach to study the impact of schizophrenia in six patients diagnosed with schizophrenia. Ten domains of quality of life were identified as important by the participants: barriers placed on relationships; reduced control of behaviours and actions; loss of opportunity to fulfil occupational roles; financial constraints; subjective experience of psychotic symptoms; side effects of medication; psychological responses to living with schizophrenia; labelling and attitudes from others; concerns for the future; and positive outcomes from experiences.

Bengtsson-Tops and Hansson (1999) investigated the socio-demographic and clinical factors, which influenced the subjective quality of life



of 120 outpatients diagnosed with schizophrenia. Objective and subjective life conditions were identified as indicators of impaired quality of life, such as financial status and work, lack of social relations outside the family, while the psychopathology of the participants was strongly related to their life satisfaction. These findings are in concordance with previous studies such as Skantze's et al (1992) who concluded that those patients diagnosed with schizophrenia who were employed experienced a better quality of life, while the unemployed when referring to having their own family, employment and friends expressed it as a wish. However, the duration of the illness of schizophrenia may lead to different outcomes when it relates to the patient's quality of life. Kemmler et al (1997) examined the quality of life of 48 patients diagnosed with schizophrenia, with at least 20 years disease history in Austria, and found that of the life domains assessed only social relations and health influenced patients' quality of life, while work, family relations and housing did not.

The focus of the literature search now moves to consider the categories of determinants of the quality of life for patients diagnosed with schizophrenia living in the community and are discussed below.

#### 2.3.4 Sociodemographic determinants

Kaiser et al (1997) examined the impact of demographic or illness related variables on the quality of life of 440 in-patients and outpatients diagnosed with schizophrenia from Berlin, Germany and Wales, UK. The results showed that there was no significant association between sex and domains of quality of life.

Homelessness negatively influences the quality of life and it affects the living situation, the family and social relations, the employment as well the safety of the patients diagnosed with schizophrenia (Lehman et al, 1995). However, Nisson and Levander (1998) reported that the living conditions when compared in psychiatric hospitals, group homes, treatment collectives, and clients own flats show no differences in the quality of life. These findings are in contradiction with those resulting from the study done by Anderson and Lewis (2000) that compared residents of a supported accommodation facility to patients of public psychiatric hospitals. The authors report that patients in the accommodation facility experienced higher quality of life.

#### 2.3.5 Psychopathology

The positive and negative symptoms of schizophrenia have been examined in relation to quality of life by many authors. Most of them reported no influence on the positive symptoms of patients' quality of life (Capriniello et al, 1997; Larsen and Gerlach, 1996) while Patterson et al (1997) identified the positive symptoms as the predominant determinant of quality of life. However, agreement is noted referring to the negative symptoms of schizophrenia and quality of life. According to Ho et al (1998), the major determinant of quality of life among 50 patients diagnosed with schizophrenia who were examined, was their negative symptoms of the illness. Galletly et al (1997) similarly reported that negative symptoms influenced negatively on the quality of life. It has to be noted that the positive symptoms of schizophrenia refer to those which appear to reflect an excess or distortion of normal function such as: delusions; hallucinations; disorganised speech and the negative symptoms

refer to those which appear to reflect a diminution or loss of normal functions such as: affective flattening; alogia; avolition.

### **2.3.6 Treatment**

The effectiveness of antipsychotic medication is remarkable in terms of reducing the need for rehospitalisation and relapse rates of the patients. Buchanan et al (1998) examined the effect of clozapine, an atypical drug, on quality of life and found that patients' social and occupational functioning was noticeably increased.

Bobes et al (1998) investigated the effects of risperidone treatment on 362 outpatients diagnosed with schizophrenia in Spain. The results showed that among the sample, women patients who had paranoid symptoms experienced greater improvement in quality of life. It can be noted that those results would be expected due to the fact that the main effect of the treatment is the reduction of the symptoms, which can lead to the improvement of symptoms related to quality of life aspects.

Moreover, pharmacotherapy in schizophrenia can affect the quality of life of patients' diagnosed with schizophrenia negatively (Green et al, 2001). Schizophrenia treatment is based on medications which often have side-effects which influence patient's functioning and their ability to engage in social interactions (Collins et al, 1991; Bellack et al, 1990). Failure to treat symptoms and the presence of side effects are associated with poor quality of life for patients diagnosed with schizophrenia (Young et al, 1998).

Keks (1997) stated that the impact of antipsychotics can improve patients' quality of life, but the side effects can diminish the quality of life.

### 2.3.7 Stigma

The distinction between mental and physical illness is clearly stated in the two latest major official diagnostic manuals: the International Classification of Diseases (ICD-10, 1993) and the Diagnostic and Statistical Manual (DSM-IV-TR, 2000). Even though the classification systems are a valuable tool for the doctors in terms of diagnosis, there is a high risk of separating the mind illnesses from the body illnesses. Such a separation implies that illnesses are different by leading to perpetuate the stigma associated with the mental health patients (Kendell, 2001). Penn et al (2000) noted that it is just the name of mental illness itself that causes the “activation” of stigma.

Amongst all the mental illnesses, schizophrenia appears to be the most stigmatised, since it is associated with violent and dangerous behaviour (Angermeyer and Schulze, 2001). Fleischhacker et al (1998) stated that “myths and misunderstandings” about schizophrenia and its treatment are responsible for the stigma suffered by patients diagnosed with schizophrenia and their families. Even though the authors do not clarify what is meant by myths and misunderstandings, it seems they refer to the cultural and historical aspects of stigma.

Schulze and Angermeyer (2003) explored stigma by using 12 focus groups in Germany. They contacted 25 patients diagnosed with schizophrenia, 31 relatives, and 27 mental health professionals. The results showed four dimensions of stigma: interpersonal interaction, structural discrimination, public images of mental illnesses, and access to social roles.

The interpersonal factors, which contributed to stigma for 39 patients diagnosed with schizophrenia, were studied by Penn et al (2000), who

concluded that social skills, negative symptoms, and perceived strangeness might contribute to stigma.

Angermeyer and Matschinger (2003) explored the public attitudes towards schizophrenia and major depression among a large sample of 5025 adults of German nationality. Negative attitudes and the perception of dangerous associated with patients diagnosed with schizophrenia were found to increase the preference for social distance while there was no effect on public attitudes towards people diagnosed with major depression.

The negative public image of schizophrenia as well as the negative impression of the term schizophrenia in Japan, were found out to be the major influences on the Japanese psychiatrists' decisions to inform their patients of the diagnosis (Yutaka et al, 1999). The relation of the negative public image of schizophrenia to the culture behind the term of schizophrenia as well as the education of the public on the mental illnesses, is stated in the relevant literature. Rosen (2003) stated that stigma is culturally applied and that poor mental health literacy leads to stigma and keeps people from seeking professional help for mental health illnesses. Moreover, the work of a programme on challenging stigma associated with schizophrenia in both developed and developing countries, showed that the developing countries should be encouraged to invoke local knowledge and methods in order to create their own anti-stigma initiatives (Rosen, 2003). The World Psychiatric Association Programme to reduce stigma and discrimination has set anti-stigma projects in local communities all over the world including the education of high school pupils on mental illnesses, the creation of local media watching

groups, the introduction of consumer speakers' services, and other similar projects (Sartorius, 1998).

The Greek public image of the mentally ill was studied by Parashos (1998) who concluded that 42% of the Greek general public would refuse to employ a mentally ill person and 36% would not like to live in a neighbourhood where mental health care services are hosted.

It is notable that the patients diagnosed with schizophrenia are at a high risk of stigmatisation and they prefer to keep their illness a secret and remain socially isolated (Link et al, 1997).

#### 2.3.8 Cross-cultural differences

The concept of quality of life remains a difficult one in terms of its definition. However, the determinants of quality of life include objective and subjective elements and many authors agree that both should be taken in consideration when quality of life is assessed (Lehman, 1983; Bigelow et al, 1990; Oliver et al, 1997). Chisholm et al, (1997) stated that the determinants of quality of life are influenced by cultural and national factors.

Gaite et al, (2002) investigated the quality of life for patients diagnosed with schizophrenia in five European cities: London (United Kingdom), Copenhagen (Denmark), Amsterdam (The Netherlands), Santander (Spain), and Verona (Italy). Four hundred and four patients diagnosed with schizophrenia in contact with mental health services were randomly selected and their quality of life was evaluated by the European version of the Lancashire Quality of Life Profile. Significant differences were noted not only between the geographical north and the south area of Europe, but also

between the cities in the north. The patients diagnosed with schizophrenia in Copenhagen, which is perceived as a safe city and with a small presence of ethnic minorities, are mostly employed, experiencing formal friendships, and receiving state benefits. In London, there are many patients diagnosed with schizophrenia who are unemployed or victims of violence. In Santander and Verona most of the patients are living with family, while in the other three areas of the study the highest percentage of the patients are living alone. Even though the majority of the patients receive social benefits in Amsterdam and London the level of satisfaction is lower in Santander and Verona where only a few patients receive social benefits. The authors concluded that the cultural setting, the life style, and the local provision of services influence the patients' diagnosed with schizophrenia perception and experience of quality of life (Gaite et al, 2002). However, it should be noted that comparisons among countries with different health systems, different policies and rules in social support, different community mental health systems, as well as different cultural backgrounds is not an easy task. Furthermore, information neither on the public perception of schizophrenia nor on comparisons with general population's perspective of quality of life is provided by the authors.

A cross-national survey in Canada, Cuba, and the United States of America on quality of life, gender, and schizophrenia highlighted differences mainly in social relationships (Vandiver, 1998). The author used parts of Lehman's Quality of Life Interview and examined how 102 outpatients from the above mentioned countries, assessed their quality of life in terms of social relationships, health, living situation, leisure, finances, and general quality of life. The results showed that women diagnosed with schizophrenia in Canada

were experiencing higher social relationships than those in Cuba, while men diagnosed with schizophrenia in Cuba reported higher quality of life for social relationships than women in Cuba. The differences referring to the social relationships could be due to the different cultural background and status of men and women in Canada and Cuba. Generally, the quality of life for men and women diagnosed with schizophrenia in the three countries is not very satisfying (Vandiver, 1998).

Chan and Yu (2004) investigated the quality of life and the related factors in 172 patients diagnosed with schizophrenia in Hong Kong. The participants reported low quality of life due to the fact that they faced financial problems, unemployment, lack of opportunity to participate in social activities, which were the result of stigma and discrimination. The majority of the participants were satisfied with the health system, since it is funded through taxation and the clients can obtain free health care, as well as family support. The researchers suggested that this is due to the Chinese culture, according to which, Chinese people have very strong bonds with family members. It seems that in China the families provide the support, which is known as social support in the Western countries.

Care of the patients diagnosed with schizophrenia was provided also by family to the majority of the participants in Mubarak's et al study (2003) in Penang, Malaysia. The authors examined the quality of life of 174 community patients diagnosed with schizophrenia and revealed problems in social relations, daily activities, work and general health, and place of living. Most of the patients under study were dissatisfied with their overall quality of life. A vast majority lived with families due to the cultural notion of caring for the sick



family member on the one hand, and to the humiliating and very expensive living conditions in the mental health homes.

In another study, quality of life was assessed for 112 Moroccan patients diagnosed with schizophrenia who had never received medications and matched with samples of patients diagnosed with schizophrenia under medication in Morocco and US; these were further matched with community controls in both countries (Green et al 2001). Even though the authors report that cultural influences were not found to have an impact on quality of life domains, the patients from the United States scored higher their quality of life except in four domains which were found to have the same importance for both Moroccan and US patients: leisure time; interpersonal interactions; social support; and tolerance to stress. The main focus of the study was the evaluation of quality of life for treated and never treated patients diagnosed with schizophrenia. However it is interesting to note that no correlation is made by the researchers between the different cultural backgrounds of the sample population, as well as the role and the function of the health care system in the two countries, especially when one is listed under developed countries and the other under the developing countries.

#### 2.3.9 Place of treatment

The treatment of the mentally ill has its roots in the asylums followed by the mental health hospitals. In the early eighties, mental health services in Europe showed an interesting shift from hospital centred care to community focused care for mentally ill patients (Muijen, 1996). As a result, most western European countries have developed a variety of community psychiatric

services depending on national differences concerning the financing of health care and specifically, psychiatric care (Rossler, 1997). In Italy the replacement of the asylum system with community based mental health services took place in 1978 and It is interesting to note that the relative law has been characterised as the most “comprehensive community oriented mental health act in the Western industrialised world” (Rossler, 1997, p. 109s).

The dehospitalisation of the mentally ill has lead to comparisons of quality of life among hospitalised patients with those who receive community mental health care. Early studies have demonstrated that quality of life along with satisfaction is higher in the community settings, while in contrast symptoms and social function often remain stable (Okin et al, 1983; Gibbons and Butler, 1987).

Studies of hospital based psychiatry and community based care in Italy, the United States, the United Kingdom, and Australia have demonstrated that community care is at least as effective and uses fewer beds than hospital based care and most importantly is much preferred by the patients, even though the cost is higher in comparison to hospital based care (Tyrer, 2000).

Tansella (1996) presented data collected in South Verona, Italy, where a Community Psychiatric Service was established and which included programmes that provide in-patient care, day-care, out patient care, rehabilitation, home visits, and residential facilities. Data relative to the clinical and social outcomes revealed that the South Verona Community Psychiatric Service satisfies the patients' needs and suggests that it is possible to move from the traditional mental hospital care and to deal with psychiatric care

within community based psychiatric services. Patients diagnosed with schizophrenia are more likely to contact community mental health services while they are compared with patients suffering from neurosis (Barr, 2000).

In relation to quality of life, studies have shown that subjective quality of life is impoverished among the severe mentally ill or community based patients diagnosed with schizophrenia (Kemmler et al, 1997; Browne et al, 1996; Lehman et al, 1982).

Wilkinson et al (1995) despite the small sample size (14 patients diagnosed with schizophrenia), investigated community based psychiatric care for people with treated long term mental illness and revealed direct benefits for the patients, their families, and society, referring to stability or improvements in patients' health, social functioning, and family burden.

Rossler et al (1999) compared the quality of life of patients suffering from schizophrenia in the community and those in long-term hospitals. The patients living in the community experienced higher quality of life than the hospitalised patients and social support was found to be the main difference between the two groups.

Similar community mental health services exist in Germany. Leibe and Kallert (2000) mention that there are three types of sheltered residential facilities within the complementary community psychiatric care: the nursing home area of large psychiatric hospitals, social therapeutic hostels, and sheltered community residential care. The same authors investigated the subjective quality of life of 245 patients who were distributed over the three mentioned types of residential care. The results showed that the patients with long length of illness as well as the worst evaluations of psychopathology and

social competence experienced the lowest life satisfaction (Leibe and Kallert, 2000). It is interesting to note that the results of the above study do not show any significant differences concerning the quality of life and the specific care settings, while Brown (1996) concluded that the patients living in home residences were more satisfied even though they were more disabled. However, when discharged long-stay patients are compared with hospitalised long-term psychiatric patients in terms of quality of life, it is more than clear that the discharged patients experience higher levels of quality of life than the hospitalised ones and they prefer living in the community (Leff et al, 1996). Leff et al (1996) compared 494 discharged psychiatric patients with 279 patients who remained in a psychiatric hospital in the UK. A previous study undertaken by MacGilp (1991) in the UK showed the same results when the entire sample (48 discharged long-term psychiatric patients) reported that they preferred to live in the community than in a psychiatric hospital.

## **2.4 Measurement of quality of life**

### **2.4.1 Social Indicators of Quality of Life**

The first attempt to measure the concept of quality of life was made by scholars working in social indicators research (Draper, 1992). According to Draper (1992), the first systematic quality of life research was conducted in the nineteenth century, by a group of natural scientists (mathematicians, chemists, and naturalists) who were convinced that the tools of their disciplines could be applied to some social problems which existed at the time.

In the United States of America, interest in measuring the quality of life grew in the 1960s in order to assess many aspects of social accounting to set goals, to rank priorities, and to evaluate social programmes (Liu, 1974). Moberg and Brusek (1978) reported that the social indicators movement was the result of the demands for social accounting, evaluation and reporting and it refers to statistical measurement of social conditions fundamental to the politicians in order to make appropriate economical and social policy decisions. It is notable that the social indicators movement arose from certain social and economic phenomena. Moreover, politicians used the social indicators research to formulate policies and programmes in the United States (Draper, 1992). At the same time there was also a need for more descriptive data measuring the quality of life of society and as a result the social indicators research moved towards the direction of this demand rather than to the demand of creating social policies and conditions.

The literature on social indicators of quality of life is often classified in two types: the objective social indicators, and the subjective social indicators depending on the measurement of social phenomena or on the individual's experiences respectively (Andrews, 1974; Najman and Levine, 1981). Each of these two types is discussed below.

#### **2.4.2 Objective social indicators**

The objective social indicators provide data based on the assumption that there is a cause-effect relationship between quality of life and some specific phenomena, which refer to a given population such as crime rates, public and market goods, unemployment figures, population density figures,

and aspects of the physical environment (Andrews, 1974; Draper, 1992). These data are measurements of society or community characteristics and may have little correlation with the individual's own rating of quality of life. According to Gehrmann (1978) the objective approach of social indicators of quality of life should refer to education, health, and to aspects of the social domain, which are "measurable in objective terms". One of the major difficulties of this approach is well emphasised in his work. Many of the phenomena might be defined and measured as social or political life aspects and not just as matters of objective fact (such as: social participation, unemployment). Najman and Levine (1981) listed four principal weaknesses of objective indicators which reduce their use and which are: lack of agreement on what constitutes a high or a low quality of life, disagreement about which indicators are relevant, little concern to relate inputs to outcomes, and little understanding of the correlation of the objective conditions of life with the subjective perception of these conditions. The fact that the concept and the dimensions of quality of life remain unclear, cause these problems and had led researchers to the use of a great diversity of measures (Holmes, 1989). Moreover, some authors support the notion that the objective conditions of life are only marginally related to the subjective assessment of quality of life (Najman & Levine, 1981) and that the connection between the objective social indicators and the subjectively perceived quality of life is under question. This view has led to the development of the subjective indicators of quality of life.

### **2.4.3 Subjective indicators of quality of life**

This approach refers to survey research reports on life experiences and the evaluation of life conditions as they are perceived by the individual. Andrews (1974), an early worker in this area, viewed subjective indicators of quality of life as "perceptual indicators" and provided four reasons for developing the perceptual indicators:

- They provide "direct" measurement on individuals' assessment of their own well being.
- They permit "cross sector" comparisons necessary for resource allocation.
- They determine the aspects of life, which concern individuals and which relate to their well being.
- They offer the knowledge related to the causes and conditions, which lead to an individual's perception of well being.

However, Andrews (1974) appreciates the concerns inherent in the "reasons" listed above. He refers to validity, interpretation, completeness, and utility of perceptual indicators. Debates arise concerning how individuals evaluate their life components, how much they will respond as survey samples, and how they tend to give biased answers (Andrews, 1974).

The terms "well-being" and "quality of life" are used interchangeably by many authors (McKennell, 1978; Andrews, 1974), while other authors use these terms in the meaning of "happiness and /or satisfaction" (Zautra and Hempel, 1984). According to Diener (1984) subjective well-being has three hallmarks: first, it is subjective in that it refers to the individual's experiences;

second, it includes positive measures and it is not just the absence of the negative factors, even though the relation between negative and positive factors is not fully understood; and third, it is based on a global evaluation of life rather than on an evaluation of specific life domains. Similarly, Veenhoven (1991) states that well-being refers to the person's evaluation of the overall quality of life, which is based on his or her affects and thoughts. Affects refer to the pleasantness experienced in feelings, emotions and mood.

On the other hand, the meaning of well-being is associated with happiness and satisfaction and authors agree that people ought to try to improve happiness in their lives, and that it is better to be happy rather than to suffer. This notion is rooted in the ancient Greek Philosopher Aristotle, who stated that happiness ("eudaimonia" was the original term he used for happiness) is the only final and sufficient value, which when once attained nothing else is desired (Diener, 1984). However, Gill (1984) lessens the meaning of happiness to pleasure and euphoria. The use of the term "happiness" in correlation to quality of life is given as "the gap between expectation and achievement". This could be the explanation for why different individuals respond differently in objective conditions and can be satisfied or dissatisfied with the same objective conditions (Kennedy et al, 1978). In the same way, McCall (1975) viewed happiness and satisfaction as the result of the fulfilment of a person's needs and wants. Since wants and needs vary from one person to another, the relationship between objective conditions and subjective assessment is weak (McCall, 1975).

The selection between objective and subjective indicators to measure quality of life is not an easy task and it depends on the availability of data and



on the subjective estimation of the investigator (Gehrmann, 1978). The main problems arising in measuring quality of life are reported by Gehrmann (1978) and are as follows:

- The concept of quality of life is too broad including many life concerns.
- Objective indicators do not offer representative findings and refer to the objectively measurable and available data, without estimating the subjective data.
- Subjective indicators take into account the different satisfaction / dissatisfaction degrees.

Since many authors recognise the problems of each approach, they agree that quality of life assessments should include both types of measure (Lehman, 1983; Gehrmann, 1978; Najman and Levine, 1981).

## **2.5 Community mental health care in Greece**

In Greece, as in other countries in Southern Europe, with the exception of Italy, changes in the legislation and decentralisation system of mental health care delivery have taken place in the mid-1980s, while in Northern Europe community psychiatry was introduced in the late 1960s and early 1970s (Madianos, 1994). Community mental health services include day hospital mental health care, hostels, and community mental health centres, which all connect to and relate to mental health hospitals. The community mental health centres refer to the patients with mental ill health of specific geographical areas and provide care at hostels, protected homes, daily

scheduled activities for clients, visits at homes, medical and nursing support, as well as psychological and social support.

During the past two decades, many organizational changes within the mental health care system have taken place in Greece, under the name of the Greek psychiatric reform. The Greek psychiatric reform started in 1984, after special funding by the European Community and under the Regulation 815/84 (Stefanis et al, 1986). The focus of the psychiatric reform was not only on the mental health care but also on the psychosocial and vocational rehabilitation of the psychiatric patients (Bellali and Kalafati, 2006).

The main pillars of the psychiatric reform included the reduction of the number of the hospitalized patients with mental ill health, and the improvement of the mental healthcare services and the living conditions for mentally ill residents in psychiatric institutions (Madianos et al, 1999). The implementation of the psychiatric reform led to a number of initiatives, which include the introduction of the community mental health services, half-way houses, nursing homes, sheltered homes, and vocational workshops for the mentally ill (Bellali and Kalafati, 2006). The main function of the mental health community centres is to provide care and treatment to patients in need according to catchment area (Madianos 1999). In those centres the patients with mental ill health receive medical treatment, psychotherapeutic interventions, counselling support for them and their families, social interventions for pension and welfare issues and sensitization of community on mental health issues. The therapeutic team coordinates and collaborates with psychiatric and other medical services in general hospitals.

Bellali and Kalafati (2006) described the current residential structures for the psychiatric outpatients in Greece as follows:

- Ambulatory mental health units in areas with particular problems of access such as islands and remote mountainous regions.
- Specialized psychiatric services adapted to the particularities of the target group, for example, drug addiction, alcoholism, autism, Alzheimer's disease, etc.
- Day care centres for adults, adolescents and children.
- Half-way houses, nursing homes and sheltered homes for the accommodation of 3500 persons who were hospitalized for a long time in psychiatric asylums.
- Half-way houses and nursing homes for patients with autism.
- Special counselling services to meet the needs of families caring for the mentally ill person.
- Special units for sheltering of patients treated under Penal Code (Article 69) in collaboration with the Ministry of Justice.

Half-way houses and nursing homes usually accommodate 20 residents for up to three months, since the overall aim is the transition to more autonomous and long term stay, the sheltered homes. Patients are monitored on a 24 hour basis and participate in training in order to promote social skills, self care, interpersonal relationships, and adaptation to working environments.

In sheltered homes, the number of residents is four or less and the selection criteria refers to the severity of the illness, meaning that non- chronic patients can be admitted, to the personal and family problems they may

experience, and to the need for supportive medication and psychotherapy in order to reintegrate into the community.

Karastergiou et al (2005) studied official reports and relevant publications in order to describe the ongoing process of psychiatric reforms and the current situation of mental health services in Greece. Findings showed that a substantial number of community mental health services have been established and the standards of care have been improved. Furthermore, new legislation has been introduced and the stigma attached to mental illness has gradually reduced. The authors concluded that the mental health centres had not yet fulfilled their role as principal providers of psychiatric care and that the mental health services were still to be completed.

#### 2.5.1 The function of the community mental health centre where the study took place

The community mental health centre where the current study took place is part of one of the main psychiatric hospitals in Athens. Psychiatric patients are appointed to the centre after they are discharged from the psychiatric hospital and they are considered as outpatients. In order to be admitted to the centre, they should be residents of the area where the centre is located, their mental health should be under follow up, and they should consent to receive follow up at the specific centre. The specific community mental health centre was established in 1976 and is divided into two sections: the adult section, where the study took place, and the children's' section.

The adult section of the centre is managed by seven physicians specialized in mental health, two psychologists, one sociologist and six registered nurses. One nurse serves as the head nurse of the centre. The follow up of the patients who are admitted to the specific centre, takes place under a routine schedule. The patients fix their appointments after coordination with the nurses and they visit the centre in order to talk with the nurses appointed to them, to discuss their problems and concerns related to their illness. Every day, one nurse serves additionally as the nurse on duty for emergency visits. The nurses appoint the patients to the doctors or the psychologists. In cases of emergency the patients visit the centre without an appointment and are admitted by the nurse who is on duty. Once a week the medical and nursing team meet and discuss the cases of the patients who are expected to visit the centre, in order to facilitate their follow up. By the end of each week the same teams meet to discuss the cases of the patients who have already visited the centre. Once a month, one nurse and the sociologist visit patients who are registered to the centre and who cannot move from their homes due to physical disabilities. The mental health physicians are responsible for the patients' medical follow up.

The centre runs a day mental health department, one wood sculpturing work shop, one dry flower composition work shop, one sewing work shop, and one shop. Specialists to the above mentioned areas of expertise are employed and teach the patients on the specific area of work. Two health professionals trained in mental health are occupied in each work shop and accompany the patients during working sessions. One registered nurse visits

the work shops on a daily basis and is the point of contact between the centre and the work shop areas.

The patients produce wooden sculptures and composite dry flowers. They also sew and produce simple home accessories such as pillows, curtains, and seasonal items. All the products are exhibited in the shop (Lotos Shop) and are sold to the public. All the work shops along with the Lotos Shop, are occupied by a large number of patients whose mental health status allows them to work under supervision. The working hours in the work shops are from 09.00 till 14.00 every week day. The budgeting for the entire centre's activities is covered by the Greek government and the patients who are occupied in the work shops and the Lotos Shop receive a small allowance every month.

The Greek government offers the centre a specific number of apartments to host some mental health patients. At the time of the study, the centre supervised four apartments and a hostel. Each apartment hosts two people and the hostel 20 people. There are specific criteria for the patients who are chosen to live in those accommodations and their stay is perceived as the test-phase before they are ready to live without supervision, either with their families or alone.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY AND METHODS**

#### **3.1 Introduction**

Mixed research methods were employed for the current study, which took place in two phases. Within this chapter the distinction between methodology and method is discussed, in order to provide the theoretical framework and the procedures which were applied during the two phases of the current study. The two main theoretical frameworks: the positivist and the naturalistic are reviewed in the beginning of the chapter. The naturalistic framework guided the researcher of the current study to choose mixed research methods and to combine qualitative and quantitative methods. The strengths and weaknesses of the research methods are discussed and studies employing qualitative, quantitative, and mixed methods are reviewed. The two phases of the current study are described at the end of this chapter.

#### **3. 2 Theoretical Framework**

##### **3.2.1 Paradigms and Nursing Research**

According to Polit et al (2001) methodology refers to the underpinnings that established disciplines have incorporated in their traditions. More specifically, research methodology is a code of rules set down before conducting research and which is accepted by a community of researchers (Dickoff et al, 1992). It is the theoretical thinking governing the study and the design of the method, while method refers to the procedures and instruments,

which are to be applied. Research methods refer to the specific techniques which are employed by the researchers in order to structure a study and to gather information according to the research question (Polit et al, 2001). Therefore, it was perceived as essential to first examine the theoretical framework (or paradigm) which would guide the study and the design of the method and then second to examine which would be the appropriate instruments for use.

Nursing research is guided by two main theoretical frameworks or paradigms: the positivist and the naturalistic paradigm (Polit et al, 2001). A paradigm is a general and theoretical perspective or philosophy towards the complexities of the world; it refers to a generally accepted worldview within a discipline (Chinn and Jacobs, 1987). The paradigm implies the philosophical perspective or basis, which guides the researcher to choose the appropriate method when conducting research. Philosophical basis refers to the way in which the investigator seeks to understand the items under study (Kuzel, 1998). Positivists seek the causes of phenomena while the naturalistic researchers are more interested in how the world is experienced by the people they study. The purpose of inquiry also distinguishes these two research paradigms. Positivist inquiry is focused on the verification of preconceived hypotheses (Kuzel, 1998). Hypotheses are set by the investigator who has a preconception about the relationship between the variables under study and seeks to prove or disprove the idea.

The positivist paradigm is rooted in the 19<sup>th</sup> century philosophical thinking and assumes that an objective reality exists due to a specific cause (Polit et al, 2001). The fundamental philosophy lies on the belief that the



phenomena do not merely occur, but they exist due to specific reasons and causes. Positivism refers to the assumption that scientific inquiry should be empirical, and centred on the verifiability principle of meaning and logical analysis. In the positivist or empirical paradigm, knowledge is developed by observing the natural world through senses, in order to verify and justify theories (Monti and Tingen, 1999). Therefore, positivists examine the nature of the phenomena and the relationships between them, in order to understand the causes of the phenomena.

Positivists are guided by five principles as below:

- Logic of inquiry is the same across all sciences.
- The goal of inquiry is to explain and predict.
- Scientific knowledge is testable through disciplined procedures.
- Research should be mostly inductive.
- Researchers must be careful not to let "prior knowledge" bias their research.
- Science should be judged by logic.

The naturalistic or interpretative paradigm is the main alternative type of methodology when conducting nursing research. The naturalistic paradigm assumes that knowledge derives from sources rather than senses and that reality has multiple meanings (Monti and Tingen, 1999). Phenomena are studied as they occur in their natural environment therefore, the researcher does not intend to use a fixed design but allows the design to emerge as new information evolves (Kuzel, 1998). Naturalistic research's purpose is the discovery of hypotheses, as well as verification, and this is accomplished by

studying the phenomenon, as it exists (Kuzel, 1998). Naturalistic inquiry avoids the constraint of hypothesis verification at the start of investigation, attempting instead to discover relationships and interpret the reality that exists in people's mind and which can later be tested and verified (Polit et al, 2001). Therefore, the naturalistic researcher seeks to understand the phenomenon under study by interpreting reality, which is achieved by being in interaction with the participants in the study. The major assumptions of the two nursing paradigms are listed in Table 1.

**Table 1**  
**Assumptions of Positivist and Naturalistic Paradigms**

<b>Positivist / empirical paradigm</b>	<b>Naturalistic / interpretative paradigm</b>
Real phenomena driven by real causes	Reality is subjective and constructed by individuals
Knowledge derives from senses	Knowledge derives from sources
Examines the nature of the phenomena	Discovers relationships and interprets reality
Uses disciplined procedures to test the researcher's ideas	Interpretations are based on the participant's experiences
Uses quantitative research approaches to gather and analyse information	Uses qualitative research approaches in order to understand the phenomenon under study

The positivist and the interpretative paradigms provide the researcher with theoretical guidance towards the implementation of the appropriate method or approach, in order to answer the research questions. Quantitative research methods are usually but not exclusively associated with the positivist paradigm while the qualitative ones derive from the interpretative paradigm.

### 3. 2. 2 Qualitative research method

The qualitative research approach is employed in order to explore human perceptions, meanings, and behaviours (Parahoo, 2006). Through the qualitative methods, the researcher can understand the meaning of the phenomena under study as they are perceived by the participants of the study. New insights of the phenomenon under study lead the research to more in-depth information, new questions arise in order to gain better understanding, and through this inductive process a theory development takes place (Polit et al, 2001). The characteristics of qualitative research include: it is conducted in a natural setting; the primary data instruments are human; there is no attempt to generalise; and purposeful rather than random sampling methods are used (Guba and Lincoln, 1989). Furthermore, the qualitative approach is most appropriate when seeking to describe the phenomenon under study from the "native" point of view (Field and Morse, 1985). Methods of qualitative research include grounded theory, ethnography, and phenomenology. A brief description of these qualitative methods is given below, in order to make clear why the researcher chose to use the phenomenology method for the first phase of this study.

Grounded theory is a research method used to collect and analyse qualitative data in order to develop theories in real world observations (Polit and Hungler, 1995). The grounded theory method is suited to the investigation of the topics about which little is known (Benton, 1991). The aim of grounded theory approach is to describe how a group of people define reality through social interactions (Hutchinson, 1986). Data are gathered by field techniques and from documents and publications (Stern, 1985). Field techniques involve

observations, interviews, video or audio taping, and it requires close relations with the informants (Benton, 1991). However, data collection for grounded theory involves a process in which data from one interview are analysed before conducting the next interview (Pidgeon, 1996). From this, it is possible to introduce information into subsequent interviews, which is 'grounded' in the information collected from earlier interviews. Therefore, the aim is to analyse data rather than using a specific technique of data collection. The term grounded theory refers to the emerging theory from this type of work. The information is gathered directly from the sample and places emphasis upon the individual's perspective of their experience. Gee et al (2003), used the grounded theory approach to study health quality of life in six individuals with a diagnosis of schizophrenia, in an attempt to explore the impact of schizophrenia on the participants' health and quality of life. Similarly, Humberstone (2002) used grounded theory by audio taping for one semi structured interview thirteen participants. The aim of the study was to develop a social theory that is grounded in individual's experience. Another study using the grounded theory method explored natural cognitive coping strategies in schizophrenia (McNally and Goldberg, 1997). The authors proposed a concept of 'coping self talk', which they derived from nine lower level analytic categories but did not extend these findings to the stage of theory generation. Chiovitti and Piran (2003) conducted a grounded theory study in which 17 psychiatric nurses were interviewed about their meaning of caring for patients in the hospital. The aim was to develop a theory within psychiatric nursing practice.

The first phase of the current study aims to explore the meaning of quality of life as it is lived by the patients diagnosed with schizophrenia in the community setting in Greece. In the beginning of the journey of this study, the researcher considered employing the grounded theory approach in order to explore the meaning of quality of life and then to develop a theory for the psychiatric nursing practice. That means that the researcher would focus on analysing qualitative data towards the development of an integrated explanatory scheme (Polit and Hungler, 1991). Following a search of the relevant literature the researcher of the current study explored the existing studies on the phenomenon of quality of life. The researcher realised that her focus while analysing the data, should be on categorizing the aspects of quality of life as they would be expressed by the informants, rather than focusing on emerging theoretical concerns in order to develop a theory on quality of life for patients diagnosed with schizophrenia living in the Greek community.

Ethnography is a systematic observation, description, documentation, and analysis of the life aspects of a culture or sub-culture in order to grasp the life ways of people in their environment (Leininger, 1985). The focus of ethnography is on individual or shared views and values related to a specific culture (Maggs-Rapport, 2000). Ethnography attempts to discover the knowledge people use to mould their behaviour and interpret their experience (Aamondt, 1989). The researcher who uses ethnography becomes part of the culture or subculture being studied through interpersonal contact with the informants (Germain, 1986; Stevens et al, 1993). When the focus of the researcher is on discovering what is happening, how it is happening, and the

meaning of what is happening, ethnography is the most appropriate method (Leininger, 1985). The ethnographic approach may include observations and interviews. A two-year ethnography conducted among 16 dually diagnosed clients yielded two longitudinal findings. First, four “positive quality of life” factors were strongly correlated with clients' efforts to cease using addictive substances and second, the study revealed that five “negative background factors” in participants' childhood homes were predictive of long-term continuation of substance use (Alverson et al, 2000). In another ethnographic study, Becker et al (2001) compared vocational and nonvocational outcomes of clients of two community mental health centres that underwent conversion from day treatment programs to supported employment programmes with outcomes of clients of a centre that delayed conversion until after the study was completed. Muir-Cochrane (2001) used the ethnographic approach to investigate the day-to-day work practices of a group of five community mental health nurses in one of four regional community mental health centres in Adelaide, South Australia. The researcher observed the work of nurses in their daily interaction with clients and his observations and experiences were systematically recorded in field notes and a personal journal while formal and informal interviews were conducted with nurses about their perceptions of managing their workloads.

Ethnography concentrates on the participants' daily lives, allowing them to describe their culture (Maggs-Rapport, 2000). Specific questions concerned with the working culture enabled the researcher to explicate the nurses' understanding and account for their daily situations at the work place.

The aim of the current study is to explore the meaning of quality of life for the patients diagnosed with schizophrenia living in the Greek community. The aspect of culture is not of interest to the researcher even though culture may be a factor influencing comparisons between the outcomes of this study and the relevant literature. Informants of the current study will be called to define what quality of life means to them and with the researcher they will take a journey through their daily lives in order to make the meaning of quality of life better understood to the researcher. The focus of the researcher is the experience of quality of life itself and not in relation to the informants' cultural values and beliefs.

Phenomenology is the method used to describe the meaning of humanly experienced phenomena through the analysis of participants' descriptions (Parse, et al, 1985). Phenomenology is both a philosophy and a research methodology (Swanson-Kauffman and Schonwold, 1988). As a philosophy it attempts to understand the world of human experiences and as a research methodology, it attempts to describe lived experiences, as they are perceived by human beings (Stevens et al, 1993).

Phenomenology is rooted in the work of Husserl, a German philosopher whose work was built on by his student, Heidegger. Husserl's focus is on the lived experience itself (Schultz and Cobb-Stevens, 2004) while Heidegger's theory focuses on the lived experiences as they are perceived and understood; as the perception reveals to the person at the moment when phenomena are constituted (Morse and Field, 1996). The goal of the phenomenological research is to uncover the essence of an experience in such a manner that the researcher uses discussions, reflection, and writing in

order to “transform the lived experience into a textual expression of its essence” (Van Manen, 1990, p. 36). The essence of the phenomenon under study is understood through the researcher’s experiences and in this way the researcher reflects on the phenomenon to be. In order to achieve reflection, phenomenologists use conversations with others, search the literature for descriptions, and engage their imagination to modify relevant experiences (Morse and Field, 1996).

In phenomenology the researcher’s views about the phenomenon being studied are made clear early in the planning of the study and finally in the report of the study (Parse et al, 1985). The intent of the researcher in analysing the data is to uncover the lived experience for the subject. This requires experienced researchers in phenomenology so they can be open to the messages emerging from the data.

Hörberg et al (2004) used phenomenology in order to describe how persons suffering from mental illness perceive their relationships with nursing staff in local authority psychiatric services. Data were collected through semi-structured recorded interviews with 17 strategically chosen clients. A qualitative phenomenological approach was used to analyse the data and four main categories and 13 subcategories emerged from the analysis. In a similar study, Moyle (2003) used the phenomenological approach to study the importance of the therapeutic relationship through the investigation of the experience of being nurtured while depressed. Seven participants, in a private psychiatric hospital in Brisbane, Queensland, Australia, were interviewed about their experience of being nurtured. Koivisto et al (2002) applied a phenomenological approach in order to explore the experiences of nine



psychotic patients about being mentally ill with psychosis. The authors conclude that phenomenology focuses on the informants' subjective experiences in a deliberate way, emphasising in this way the notion that phenomenology can explore the meaning of experiences as they are lived by people with schizophrenia.

### 3.2.3 Phenomenology in the Nursing Science

In the late 1970s and in the decade of the 1980s following the growth of nursing research, the need to examine the philosophical basis of nursing became the core interest of nurse researchers. As a result, questions arose as to what constitutes nursing as a science, what should be searched within nursing, and how should nursing be researched (Nicoll, 1992). Theoretical nursing models emerged as an effort to extend existing theories from other disciplines within nursing such as that of Martha Rogers in 1970, based on the nature of health and human experience, Parse's nursing theory of human becoming in 1981, King's theory of goal attainment in 1981 (Chinn and Jacobs, 1987). Rogers viewed nursing as the science with the central concern of unitary human beings and provided a new way of thinking about people, nursing, and health (Lutjens, 1995). Parse's human becoming theory is a synthesis of the Rogerian view of the world and the existential phenomenological philosophies of Heidegger. The research method emerging from Parse's human becoming theory is a phenomenological method in that the phenomena under study are experiences as described by those who have lived them (Parse, 1995). King viewed the focus of nursing as the exchange of

information between human beings with their environment in ways that lead to self fulfilment and maintenance of health (Tritsch, 1998).

The purpose of this chapter is not to review existing nursing theories. Nursing literature includes a numerous amount of books and articles on nursing theories, their assumptions and principles and their implementation in both nursing practice and research. However, it is important to note that the nursing frameworks serve as the basis for understanding the self as human being, nursing as a science, and nurses as professionals. It is believed that theoretical perspectives are necessary for discipline specific research.

Cody (2000) stated that the selection criterion of a theoretical framework is based on whether the theory “speaks” to the nurse and through which the nurse “sees” himself or herself. For example, nurses guided by Roger’s theory of unitary human beings, view themselves as energy fields and together with the patient/person participate in patterning towards optimum health potential. Nurses guided by Parse’s human becoming theory dwell with the meaning of lived experiences and concerns of the persons they serve. Nurses who are interested in human experiences and in a rigorous, critical, and systematic method to enhance knowledge about lived experiences, employ phenomenological research (Parse, 1995).

Due to its focus on the detailed description of an individual's experience in the world, phenomenology can meet the needs of nurse researchers who wish to focus their research to a greater degree on personal ways of knowing, on questions of being, and on multiple realities (Van der Zalm and Bergum, 2000). Yegdich (2000) supports this notion and goes on to state that phenomenology is “aligned” with the humanistic doctrines of nursing

in the sense that both investigate the experiences of people. According to Van Manen (1990) phenomenology brings perceptions, descriptions, and language towards the enhancement of understanding.

Phenomenological research is seen as a co-creation between researcher and participants rather than an observation of objects or behaviours. Phenomenology is the research method that could provide understanding of the person's lived experiences, valuing the nurse – patient relationship as well as viewing the person under a holistic approach (Van der Zalm and Bergum, 2000). The philosophical orientation of phenomenology to understand the meaning of the person's experiences appears to be the appropriate approach when experiences of health or illness are under study (Benner, 1985). The individualistic nature of nursing is relevant to the values and beliefs of the philosophy of the phenomenological approach, which focuses on the notion that the phenomena can only be explored through the meaning as it is given by the individual. Jasper (1994) examined the design and the data analysis of the phenomenological research method and concluded that the phenomenological research method has a great deal to offer to nursing as a humanistic discipline.

#### 3.2.4 Quantitative research method

Based on the assumptions of the positivist paradigm, the quantitative researcher believes that there is one reality of what is called the "truth" and it can be defined by measurements. Through deductive reasoning, complex situations are broken down to simple parts in order to understand the whole. The goal is the generalization of the results to the population from which the

study sample was drawn and which is referred as the main criterion in assessing the quality of the study (Polit et al, 2001). Quantitative methods are perceived as highly objective and the researcher believes that he or she should remain detached from the study and the participants in order to gain objectivity. The researcher's subjectivity should not influence the measurements of reality (Cormack, 2000). Furthermore, the researcher uses precise measurement tools in order to generate numerical data, which are analysed statistically (Cormack, 2000). There are three types of research falling under quantitative research: descriptive, correlational, and experimental research. The instruments used when conducting quantitative research are questionnaires, structured interviews, and observations, which are organised and structured (Cormack, 2000). The data collected from both interviews and observations are manipulated numerically.

The descriptive approach is employed when the researcher's aim is to discover new meanings, determine the frequency in which a situation/variable occurs, and to categorize information (Burns and Grove, 1999). Chan and Yu (2004) used the descriptive approach in order to investigate the quality of life in clients with a diagnosis of schizophrenia in Hong Kong. A convenience sample was recruited from a psychiatric outpatient department and structured interviews were conducted using the Brief Psychiatric Rating Scale and the Hong Kong Chinese World Health Organization Quality of Life Scale-Brief Version. Hellzen et al (2003) employed the descriptive approach by using a questionnaire in order to examine the nurses' views of a caring approach for a fictitious older long-term resident suffering from schizophrenia. Findings

showed that there appeared to be a tendency for long work experience to have a negative effect on nurses' attitudes towards the resident.

Correlational research refers to the type of the quantitative approach in which the researcher's aim is to investigate and explain the nature of the links between the variables (Cormack, 2000). In correlational studies, questionnaires are used in order to provide data to support or reject hypotheses; in this way knowledge is produced deductively (Parahoo, 2006). Huppert et al (2001) examined the relationship between quality of life and symptomatology in 63 stabilized outpatients diagnosed with schizophrenia. Findings showed that severe depression, as rated on the Brief Psychiatric Rating Scale (BPRS) was associated with lower general life satisfaction and lower satisfaction with daily living, finances, health, and social life. In addition, higher anxiety ratings on the BPRS were associated with less satisfaction with global quality of life, daily activities, family, health and social relationship, even when controlling for positive symptoms, negative symptoms, or depression. Anxiety was also significantly correlated with a number of positive and negative symptoms. In the same way, Doyle et al (1999) assessed the way in which insight influenced patients' diagnosed with schizophrenia evaluation of their objective life conditions. Forty outpatients diagnosed with schizophrenia were interviewed using the Lancashire Quality of Life Profile and the Standard of Living Interview while insight was assessed using a self-report questionnaire, the Insight Scale. Results revealed a significant correlation between objective and subjective indicators of quality of life.

Experimental research is employed for testing cause and effect relationships and due to its rigorous control of variables, it is perceived as the

most powerful qualitative research method (Cormack, 2000). However, when conducting experimental research, the problem of the Hawthorn effect is of major concern (Polit et al, 2001). The Hawthorn effect refers to the effect of the environment on the participants. Being in a study may influence participants' behaviour by obstructing the effect of the variables. Most of the studies on schizophrenia treatment are based on experimental research. Allison et al (2003) examined the impact of weight gain on the quality of life of persons with schizophrenia who are taking antipsychotic medications. The Psychological Well-Being Index was distributed to 286 individuals diagnosed with schizophrenia. Results showed that 56 percent gained no weight over a six-month period while taking antipsychotic medications, 19 percent gained one to ten pounds, 12 percent gained 11 to 20 pounds, and 14 percent gained more than 20 pounds. The authors concluded that weight gain was related to poorer quality of life and reduced well-being and vitality. Galletly et al (1997) examined the reduction in symptoms, changes in neuropsychological test performance and improved quality of life in 19 outpatients diagnosed with schizophrenia treated with clozapine. The authors concluded that reduction in both negative symptoms and general psychopathology was associated with a better quality of life.

For the second phase of the current study, correlational research was employed by the researcher. Having extracted the domains of quality of life for the patients diagnosed with schizophrenia living in the community, the researcher's aim was to measure quality of life in relation to these variables. The selection of the appropriate quantitative tool is discussed in Chapter Six.

### **3.3 Combining qualitative and quantitative methods: mixed methods**

The decision regarding which research method is the most appropriate to use, depends on both the phenomenon under study and on the researcher's characteristics (Parahoo, 2006).

For the current study, the researcher chose to combine the two approaches and to employ qualitative research method for the first phase of the study and quantitative method for the second phase. The researcher believes that the experience of quality of life for the patients diagnosed with schizophrenia who live in the community, can be described only by the patients themselves. The interpretative paradigm is aligned with the researcher's values and beliefs and phenomenology provides the appropriate method to describe and understand the meaning of quality of life as it is experienced by the patients diagnosed with schizophrenia under study. The data which were collected through semi structured interviews were analysed qualitatively. A quantitative tool, a questionnaire, was then chosen in order to measure quality of life for the patients diagnosed with schizophrenia living in the community in Greece.

The use of mixed research methods has received a lot of criticism within the relevant literature. Quantitative research is criticised as limited in researching meaning, experience, and behaviour while on the other hand qualitative research is argued to be subjective, and lacking in validity, reliability, and generability (Parahoo, 2006). However, questions arise concerning whether or not qualitative and quantitative approaches should be combined, whether or not the product of the mixed methods should constitute a third research approach, and whether or not the mixed methods should link to

mixed paradigms. Sandelowski (2000), referring to mixed methods stated that mixed methods are not mixtures of paradigms and that the paradigms are reflected in the techniques researchers choose to combine. Leininger (1994), an interpretative nurse theorist, argued that the two paradigms are so different that they cannot be “reconciled”. McEvoy and Richards (2006) refer to the “purist” methodologists to describe those who are in strong favour of one method, either qualitative or quantitative, and who believe that there are almost no commonalities between the two methods. However, the mixture of qualitative and quantitative methods should depend on the aim of the research and it should lead to a final outcome which benefits from both approaches. Johnson and Onwuegbuzie (2004) supported this notion by stating that researchers should employ whatever methods are necessary in order to obtain optimum results, even if they have to move from one paradigm to the other. Neither approach is superior to the other and both have strengths and weaknesses (Carr, 1994). However, combining the two approaches has the potential to lead to greater insights than those which would be gained by employing one approach alone (Simons, 2007). According to Parahoo (2006, p.89), the purpose of combining methods is to achieve one or more of the objectives listed below:

- to develop and enhance the validity of instruments
- to further explore or test the findings of one method
- to develop, implement and evaluate interventions
- to study different aspects of the same topic
- to explore complex phenomena from different perspectives and



- to confirm or cross-validate data.

The researcher of the current study used mixed methods in order to study the phenomenon of quality of life for the patients diagnosed with schizophrenia living in the community in Greece. In order to achieve the fourth objective as mentioned by Parahoo (2006), in the first phase of the study, the researcher explored the meaning of quality of life by using a qualitative method and semi structured interviews, in order to gain an understanding of the informants' lived experience of quality of life. In the second phase, the researcher explored the links between quality of life and such variables as gender, education, age, duration of sickness, and future expectations. The two methods were integrated in the present study with the second method emerging out of the data collected during the first phase. It has to be mentioned that this mixture of methods in reality could be perceived as in fact two studies, each looking at different aspects of the phenomenon under study (Parahoo, 2006). However the combination of both methods was perceived by the researcher as the most appropriate way to first defining the meaning of quality of life as perceived by the informants themselves through the use of interviews and second to measure the patients defined quality of life by using the appropriate quantitative tool.

Voruganti and Awad (2002) used empirical study approaches and qualitative methods of data analysis, in exploring the quality of life of mentally ill individuals during antipsychotic drug therapy. The domains and items of the questionnaire were derived from four sources: review of literature, consultation with experts, individual interviews with patients and care givers, and patients' focus groups. They employed mixed methods to ensure that

they fully explored the meaning of quality of life for the specific target group using the data derived from each one step of the study.

### **3.4 Paradigms, nursing theories, and nursing research in Greece**

Nursing theories are not well known in Greece and only a few of them are taught in Greek nursing schools, however not extensively. Nursing practice is mostly guided by procedures and standards on patient's care and not by a specific nursing theory. The roots of nursing practice are founded in the religious values arising from the Greek Orthodox Church guidelines, based on love, respect, and devotion. Specific nursing care skills for use in the clinical practice are gained through education programmes in medical, surgical, paediatrics, and psychiatric nursing specialisations. The focus of the nursing curriculum is on the pathology of the diseases, the treatment in relation to the medical therapy, the expected potential outcome of the treatment, and the nursing interventions towards the patient's response to the treatment. It could be characterised as a sub-medical model enriched with the aspect of care and caring which is the core difference between the medical and the nursing sciences. As a result, nursing research in Greece is mostly guided by the positivist paradigm by using quantitative research methods which are influenced by medical research. Qualitative methods are not often employed by Greek nurses while doing research. One possible reason would be the broad Greek notion that a research method should provide usability in order for findings to be applicable to nursing practice. In many cases interviews are perceived as an easy and fast way to collect data and are not professionally accepted in the scientific era. During the past two decades, the

nursing departments of the main universities across the country have moved towards a scientific way of teaching, practicing, and perceiving nursing within the Greek scientific society. The number of nurses holding post graduate degrees has been increasing and the role of the scientific nursing associations has been revised in order to assist nurses to move from the traditional religious aspect of delivering nursing care and to professionally develop themselves within the nursing science. The influence of the European and trans-atlantic nursing, along with the increasing number of nurses who take postgraduate degrees abroad, places hope that nursing in Greece will find its scientific way to move towards a scientific path of knowledge, theorising and practicing.

The author of the current study became familiar with the nursing theories twelve years ago while taking her Master's degree in Nursing Science in 1995. She studied nurse theorists coming from both the positivist and the interpretative paradigm and realised that her values and beliefs are more fitted to Parse's human becoming theory and to the phenomenological approach to research. Therefore, the researcher chose Parse's theory for her Master's research proposal and chose to use the phenomenological approach for the current study as it clearly fits with the research aims and objectives.

### **3.5 The current study**

In order to explore patients' diagnosed with schizophrenia perceptions on quality of life, the choice of the methodology emerged after the extensive search of the relevant literature review. Integration of qualitative and

quantitative approaches was the chosen methodology for the current study, in an attempt to enrich as many areas of inquiry as possible.

Polit et al (2001) identified the rationale and assumptions for the use of the integrated designs. This rationale was implicit in its use.

- Complementarity: qualitative data on the meaning of quality of life should be expressed in the way the sample perceives it and quantitative data should represent the statistical and numerical findings through a quantitative tool which should be used.
- Incrementality: the subjective experience of quality of life should tend to be incremental relying on more than one tool.
- Enhanced validity: the integration of qualitative data should help the researcher to choose the quantitative tool and to shape the results.
- Creating new frontiers: the aim of the researcher is not just a single investigation of the meaning of the quality of life for the patients diagnosed with schizophrenia living in the community, but also to extract meaningful distinctions that merit further study.

The assumptions of the integrated design guided the whole study procedure. The researcher's aim was to combine the differences of the qualitative and quantitative approaches by understanding the meaning of quality of life as perceived by the sample and by identifying and explaining causal relationships between the meaning of quality of life and events or situations. This is what Cormack (2000) refers to as the "contrast of qualitative and quantitative methods". Furthermore, the single use of an existing quantitative instrument would not be appropriate for the purpose of the current

study, since the meaning of the quality of life has not been explored for the Greek patients diagnosed with schizophrenia living in the community. This was achieved by employing a qualitative approach, which then lead to the choice of the appropriate quantitative tool. The study took place in two phases.

### 3.5.1 Phase one

The research question for the first phase of the study was: "what does quality of life mean to you?" The purpose was to extract the meaning of quality of life as perceived by the patients diagnosed with schizophrenia living in the community in Greece. The literature review revealed a variation of definitions of quality of life, depending on the subjective perception of the persons under study (Lehman, 1983; Chisholm et al, 1997; Awad et al, 1997) therefore qualitative interviews were perceived by the researcher as the appropriate method to use.

In order to explore the meaning of quality of life as it was experienced by the informants, the researcher's first consideration was to use focus group interviews for the data collection. Focus group interview is a technique in which 5-15 people are assembled for a group discussion (Polit and Hungler, 1995). The method of focus group interviews provides the researcher with the advantage to obtain data from many individuals in a short time. The interviewer follows a written set of questions or topics to be covered by the discussion and guides the discussion. Basch (1987) emphasised the key features of the focus group interviews which include: the role of the moderator, the physical setting, the psychological climate conducive to a successful focus

group session, proper selection of participants in accordance with the aim of the focus group interview, instrumentation (development of discussion outline and questions to be asked), data collection and analysis, including a summary report on the findings.

After closer examination, the researcher decided that the focus group interviews would not be suitable. First, because it could be disadvantageous if participants would not feel comfortable to express their viewpoints in front of the other participants (Polit and Hungler, 1995). Second, while the presence of a moderator is recommended to support the researcher and reduce potential bias (Knudsen et al, 2000; Sims and Snell, 1996), it was not easy to plan the presence of a moderator due to the heavy workload in the community mental health centre.

Semi-structured interviews were employed for the data collection of this phase of the study. The aim here was to encourage the participants to talk freely about their experience of quality of life (Polit and Hungler, 1995) and at the same time to provide the opportunity to change the wording but not the meaning of the questions (Berriball and While, 1994). From the researcher's point of view, this kind of flexibility was perceived as important due to the fact that the participants of the specific study were called to be interviewed for the first time, since quantitative methods are most used in the specific community mental health centre. Furthermore, the validity of the semi-structured interviews is enhanced due to better understanding of the questions by the participants and the researcher's freedom to probe for further responses on the topic under study (Parahoo, 2006).

The first phase of the study explored the determinants of quality of life as perceived by the patients diagnosed with schizophrenia living in the community, in Greece. Furthermore, the transcribed interviews were qualitatively analysed and specific domains of quality of life were identified, in order to proceed to the second phase of the study.

### 3.5.2 Phase two

The purpose was to further expand the research question and to measure quality of life for the patients diagnosed with schizophrenia living in the community in Greece. The domains of quality of life as revealed from the first phase of the study, led the researcher to identify the appropriate quantitative tool for the second phase of this study. Polit and Hungler (1995) stated that the analysis of the qualitative data provides the researcher the understanding and the insight into the topic under study, while quantitative data helps in clarifying and shaping the findings obtained in qualitative analysis.

The literature review pointed out that there has been no study undertaken with Greek patients diagnosed with schizophrenia living in the community and that there is no Greek quality of life instrument generated so far. However, at the time when this study took place, the only instrument measuring quality of life and translated into Greek, was the Subjective Quality of Life Profile (SQLP) questionnaire. The SQLP is a 30-item, self-administered questionnaire and has previously been validated in a large sample population with somatic disorders. It has been translated in Greek and was then formulated to be used for renal patients. It is characterized by its

multidimensional pattern and subjective approach (i.e., the degree of satisfaction with various domains of life, the degree of change anticipated and the importance attributed to these domains). The SQLP was tested with three mental health patient samples: people with depression, psychosis, and substance abuse. Findings indicate that the questionnaire is useful in describing mental health patients, their characteristics, and explaining some of their changes (Dazord et al, 1998).

### 3.5.3 Ethical considerations

Formal ethical approval was sought from the Director of the mental health community centre where the participants of the study belong as out-patients. The researcher submitted the patient information sheet along with the consent form to the Director in order to obtain ethical approval for the study. The environment, where the study took place, was a large community mental health centre, in Athens, Greece. The researcher was known to that centre due to her training in community mental health for six months, one year prior to the study. That could raise several ethical considerations since the researcher could have got better results, because of knowing the participants, or less information due to participants' feelings of being "obliged" to participate. The researcher was aware of such ethical considerations and faced the potential difficulties by enabling the ethical principles of autonomy, beneficence, justice, confidentiality, privacy, and informed consent (Polit and Hungler, 1995; Parahoo, 2006). The informed consent process, should be directed not only at providing relevant information to potential subjects but also at promoting their understanding (Parahoo, 2006). This implies the need



to ensure that consent forms are written in a way that the level of difficulty suited to the reading and comprehension skills of the expected subject population. In addition to having adequate information, understanding, and freedom from controlling influences, informed consent requires that potential subjects have the capacity to make a decision about participation (Polit and Hungler, 1995). In order to facilitate informed consent, the researcher designed the consent form (APPENDIX A) and explained the participants the purpose and the nature of research, as well as what was required from them, and what may be the potential benefits and risks resulting from the study (Alderson 1998). Potential benefits were mentioned to the participants as they were expected to refer to nursing care, and better understanding of the patients diagnosed with schizophrenia living in the community. No risks resulting from the study were identified. Taking in account that prospective subjects must be able to assess the possible consequences of participation/non-participation with respect to their individual interests, and that they must be able to come to a reliable decision as a result of these deliberations, the researcher made clear to each one of the participants that they would be included in the research only if they freely and knowingly choose to participate without any consequences of their decision. The researcher let the participants talk about their quality of life in their own way, let them use their own words to express their life experiences, by making them feel comfortable to discuss how they perceive quality of life without having any intention to judge them, by assuring them that their identity would be protected and no real names would appear on any publication or official research paper, by taking the interviews in a quiet office, and by scheduling

the interview appointments to take place in such a way that the participants did not meet one another.

### 3.5.5 Sampling

The total number of the adult mental health outpatients, who had been admitted till the time of the study, was 3.000 people. The strategy of non-probability sampling was employed for the study. Non - probability sampling involves non - random selection in choosing the participants and not all the elements of the population will have a chance for inclusion in the sample (Polit and Hungler, 1995). According to Mays and Pope (1995), the purpose in using non – probability sampling is to identify specific groups of people who will enable exploration of a particular concept relevant to the research. This approach provides the researcher with flexibility to include a wide range of types of participants.

The sample inclusion criteria were as follows:

1. men and women between 18 and 65 years old,
2. admitted to the centre for at least two years prior to the time that the study took place,
3. a diagnosis of schizophrenia or a schizoaffective disorder according to DSM IV-TR,
4. being able to understand and communicate with other people,
5. living in the community within the catchment area of the services and having ongoing contact with the outpatient unit.

It has to be mentioned that the aspect of ethnic diversity was not an issue under consideration for the study since almost all of the total outpatients were of Greek nationality. The criterion 2, of having been admitted to the centre for at least two years was set by the researcher. The researcher took into account that there should be an appropriate timeframe for the participants to return to their daily activities and life in order to be able to define the quality of their lives, after their mental illness experience. The criterion 4 was perceived as important by the researcher. Having taken a one year university theoretical education and training in Mental Health Nursing, she had the experience of a number of patients diagnosed with schizophrenia who were experiencing communication problems as a side effect of their treatment. Collins et al (1991) state that schizophrenia treatment often has side-effects which influence patient's functioning and their ability to have social interactions. By establishing the above mentioned criteria, the researcher was aware of the heterogeneity of the sample and the bias emerging of this. Therefore, the main extraneous variables were identified such as: age, diagnosis, length of being admitted to the centre, in an attempt to make the sample as homogenous as possible (Cormack, 2000).

Three hundred patients diagnosed with schizophrenia living in the community met the selection criteria. Ten of them were randomly selected to participate in the first phase of the study and 90 more for the second phase of the study. The researcher randomly chose ten patients who met the selection criteria and who had fixed an appointment to visit the specific community mental health center within the next three weeks from the scheduled starting day of the interviews. Out of the randomly selected ten patients, two did not

agree to be interviewed and they expressed their wish to participate in the second phase of the study. Therefore, the final number of the participants for the first phase was 8 and for the second phase 100, including the 8 outpatients who had been interviewed. The 90 participants of the second phase of the study were also chosen randomly out of the total number of the patients who met the selection criteria and who either were participating in the daily activities of the mental health center or visiting the center on a regular basis.

## **CHAPTER FOUR**

### **METHODOLOGY PHASE ONE**

#### **4.1 Process of Phase One**

##### **4.1.1 Data collection**

The aim of the researcher was to let the participants themselves express their perceptions on the quality of life concept, therefore, semi-structured interviews were chosen for the data collection in the first phase of the study. Semi-structured interviews are conducted on a base of a loose structure and consist of open-ended questions that allow the interviewer and the interviewee to probe for further details on the concept under study (Pope and Mays, 2006). The researcher used a topic guide with a list of questions and areas to be covered with each participant (Polit and Hungler, 1995). The difference between the topic guide and the interview guide, which is used in structured interviews, is that it consists of a list of pre-formulated questions, which the researcher can either omit or add to (Parahoo, 2006). The topic guide began by asking the participants a few demographic questions such as: age, education level, family status, work employment and so on. The direct question of what quality of life meant to the interviewee, became a consideration for the researcher. According to the relevant search of the literature and due to the absence of a clear definition, the researcher approached the concept through questions on the participants' daily activities and life. Her intention was to establish a basic knowledge of the participants' daily activities and life in order to be able to follow and understand the

participants' views and experiences on quality of life. Therefore, the researcher started by asking the participants to describe their daily life and then she went on to ask what leads them to life satisfaction, fulfillment, happiness, and joyfulness. Then the researcher applied the direct question of what was giving quality to the participant's life. In this way, the researcher could identify the domains of quality of life as they were expressed by the participants. The question of prioritizing those domains was asked by the researcher in order to extract the importance of the factors which led to participants' quality of life. The Interview topic guide is showed below in Table 2.

**Table 2**  
**Interview topic guide**

Demographic questions	How old are you?
	Are you married (if yes)/ do you have children?
	What is your educational background?
Other questions	Do you work?
	Whom do you live with?
Quality of life questions	Would you like to describe your daily life for me?
	Which of your life areas are the most important to you?
	Which of these do fulfill you the most?
	What does quality of life mean to you? (In cases not understood this question had to be questioned in the way: What does satisfy you? Or: What does fulfill you?

It has to be noted that the way the researcher handled the interviews could be comparable to the unstructured interviews. Unstructured interviews are conversational and based on the sense that the researcher can ask a broad question relating to the topic under study and subsequent questions are guided by the responses to the broad question (Polit and Hungler, 1995). However, the researcher wanted to be sure that the research question would be clear to the participants and that the given set of the topics would be covered by them. When employing semi-structured interviews, the interviewer encourages the participant to talk freely about all the topics included in the guide list (Polit and Hungler, 1995).

The researcher noted that some participants were talking very fast and they were covering irrelevant issues without having been asked by the researcher to do so. That was expected by the researcher, due to her psychiatric background knowledge. According to the International Classification of Diseases-10 (ICD-10, 1993), which represents the European description of mental illnesses, one of the symptoms of patients diagnosed with schizophrenia is incoherence or irrelevant speech. The researcher had to interrupt the participant when he/she was talking irrelevant to the question issues and to bring him/her back to the interview context.

#### **4.1.2 Participants' characteristics**

Five women and 3 men were participated in the interviews. The participants' characteristics are shown below, in Table 3.

**Table 3**  
**Participant's Characteristics**

Characteristics		Male	Female
<b>Gender</b>		3	5
<b>Age</b>		42-56 years old	31-50 years old
<b>Marital status:</b>	married	1	1
	never married	1	3
	separated	1	1
<b>Education:</b>	High school completed	1	2
	Middle school not completed	1	2
	Elementary school completed	1	1
<b>Living:</b>	with parent/s	1	2
	alone	1	
	with family	1	2
	in mental health residency		1

Concerning the education level of the participants, the table above shows the highest education level certificate held by the participants at the time of the study.

#### 4.1.3 Timing of the interviews

The participants were contacted during their monthly visit to the community mental health centre. Once a month they had a fixed appointment in the centre, in order to get their monthly drug prescriptions and to see the nurse appointed to them for any potential problems they might have throughout the month. The researcher in coordination with the charge nurse of



the centre had access to the appointment book and could schedule the participants. However, there was always the risk of absence of some participants who cancelled their appointment a few hours before the fixed time, due to personal reasons. That caused some delays to the overall interview time schedule but with no consequences to the study time frame.

The interviews took place in a staff's office, which was quiet and was providing a private setting. Confidentiality and anonymity were discussed with the participants at the first place. The purpose of the interview and the overall study were addressed to them and they all signed the informed consent form (APPENDIX A).

#### 4.1.4 Validity

The interviews were recorded and notes were taken by the researcher during the interview process. Face and body expressions were also noted. The researcher clarified responses to ensure that she was getting the exact meaning of the participants' sayings (Polit and Hungler, 1995). The interviews were taken in Greek; therefore the transcripts were translated to English by the researcher. A copy of the transcripts was given to the Director of the community centre for translation too and the researcher double-checked for mistranslation or misinterpretation. However, there were not differences in the two translated documents.

#### 4.1.5 The interviews

The interviews with the participants of the first phase of the study were tape-recorded. Tape-recording provides the interviewer the advantage to

analyse the interview content later (Treece and Treece, 1986), while allowing time for observing the interviewee and to keep notes during the interview session (Cormack, 2000). Prior to the interview, each participant was asked for agreement to be tape-recorded. There was only one participant who did not like her interview to be tape-recorded and the researcher had to record by hand, all the discussions during the interview. Each interview had been estimated to last 15 to 20 minutes. However, it took longer than the estimated time due to the time spent on introductions, explanations of the purpose and the procedure of the study, and the signature of the consent forms and the information sheet by the interviewees. The consent form and the information sheet are listed in APPENDIX A.

The 8 outpatients who were interviewed included 3 men and 5 women. Three of the women were participating in the work shop programmes of the centre and one of those was living in an apartment supervised by the centre. One of the men was retired; all the subjects were under schizophrenic medication.

In the Table below, the application of the phenomenological approach is described along with the steps taken in the first phase of the study.

**Table 4**  
**Application of Phenomenological characteristics**

<b>Characteristics of Phenomenology</b>	<b>Application to the study</b>
Natural setting	Data were collected in the participant's mental health follow up centre
Human data collection	Researcher was the primary collector of data

<b>instrument</b>	
<b>Utilization of tacit knowledge</b>	Researcher relied on personal experience in the clinical area
<b>Qualitative methods</b>	Interviews were used to collect data
<b>Purposive sampling</b>	Participants were invited to participate because of their experience of being diagnosed with schizophrenia living in the community
<b>Inductive data analysis</b>	Data from interviews were analysed to identify the domains of quality of life
<b>Informed consent</b>	Participant involvement was negotiated through informed consent.
<b>Idiographic interpretation</b>	Information was requested and recorded on a individual basis and for how things were at the time of the interview
<b>Tentative application</b>	Interpretation of the data resulted in a description of the quality of life domains identified by participants. From this information hypotheses were generated about the domains of quality of life for this group of people
<b>Focus-determined boundaries</b>	The phenomenon of quality of life in a selected group of patients diagnosed with schizophrenia who were living in the community was only studied. No other aspect of role was studied and no other group of people was involved
<b>Special criteria for assessment of trustworthiness</b>	Participant generated data, verification of interpretation using two other investigators, and comparison of findings with current literature were used as criteria for establishing validity and reliability

	of data collected and interpreted.
--	------------------------------------

The four steps of the phenomenological inquiry as they are described by Polit and Hungler (1995) were applied firstly while taking the interviews and secondly while analysing the data and presenting the findings: bracketing, intuiting, analysing, and describing. Bracketing refers to the process of understanding far from preconceived beliefs and opinions on the phenomenon under study. The researcher “brackets out the world” in an effort to separate participant’s descriptions from own preconceptions. Intuiting occurs when the researcher remains open to the meanings given by the participant on the phenomenon under study. Analysing refers to identifying the structure of the phenomenon under study through the interview, which is described as the conversation between informants and researcher. Finally, describing involves the researcher’s understanding and defining of the phenomenon under study (Polit and Hungler, 1995; Morse and Field, 1996).

4.1.6 Analysis of the Qualitative Data

Qualitative content analysis was employed to analyze the data generated out of the 8 interviews. Qualitative content analysis involves an analysis of the content of the data in order to identify prominent themes and patterns among the themes (Polit and Hungler, 1995). The researcher explores the textual data inductively, identifies and integrates important themes adequately and develops a category system for coding the data (Pope et al, 2000).

Computer programmes can help the qualitative data analysis. However, the researcher of the current study explored the possibility of using such programmes, but decided a manual approach was more suitable as she was working as a single researcher, and also wanted to stay close to her data. According to Burnard (1991), there are 14 stages of data analysis. They include:

- keep notes after the interviews on the topics discussed during the interview
- keep notes while reading the transcripts and make notes
- read the transcripts again and write as many headings or category system as necessary to describe all aspects of the content
- group the list of categories together, under high-order headings and remove repetitions or very similar headings
- two colleagues generate their own category systems and they are compared and discussed along with the researcher's category and adjustments are made as necessary
- re-read the transcripts, decide which categories cover all the aspects of the interviews and code the categories to categories headings
- collect the items of each code and select participants to check the appropriateness of the category system
- refer to the sections when writing up the findings and link the findings to the literature

Initially, the data were read and re-read by the researcher to identify the quality of life indicators as expressed by the interviewees. The indicators were then categorized into themes and finally the clarification of the concept of quality of life was extracted according to the themes. This is a "reductionistic activity", according to Polit and Hungler (1995) and it converts the raw data to more manageable and manipulative units.

In order to achieve data verification, the researcher asked the charge nurse of the centre to read the transcripts and to categorize the data. Due to the heavy workload of the centre, it was not possible to get a second colleague to read the transcripts and categorise the data. There were not big differences between the categories as they had been made by the charge nurse and the researcher. However, both the charge nurse and the researcher agreed upon the final list of categories.

In the next chapter, the indicators of quality of life are listed first (Table 6) and then their categorization appears into themes (Tables 7 and 8) followed by the concept clarification of quality of life (Table 9).

## **CHAPTER FIVE**

### **QUALITATIVE FINDINGS AND DISCUSSION PHASE ONE**

#### **5.1 Findings and Discussion**

The findings of the qualitative method of this study will be presented along with their discussion. In qualitative studies, the findings are presented together with their interpretation because the task of integrating qualitative findings is necessarily interpretive (Polit et al, 2001). The aim of the researcher was to explore the meaning of quality of life, as it was perceived by the eight participants. In order to establish a basic knowledge of the participants' daily activities and life, the researcher set relevant questions. The answer given by each participant guided the researcher to go on until there was nothing more added by the participant. The participants were informed that no last names would appear on written transcriptions, reports, and published papers (APPENDIX A). However, they expressed their will to have their first names used during the interviews and appeared on the written transcriptions. It has to be noted that the participants' first names are very common among the Greek population; therefore, their confidentiality is protected. A list of the gender and the first names of the eight participants is provided below in Table 5.

**Table 5**  
**Gender and First Names of the participants**

First Name	Gender
Alexander	Male
Tasos	Male
Michael	Male
Martha	Female
Soula	Female
Vasiliki	Female
Anna-Maria	Female

### 5.1.1 General Findings

Before presenting the qualitative findings, a short introduction to the participants is provided. Alexander was 42 years old, he had graduated High School, had never worked in his life, and he was living with his mother. Maria was 36 years old, she had elementary school education, she was living alone, had never worked, and she was a single parent. Michael was 56 years old, he had elementary school education, had been married for 10 years, had no children, living alone, and had no job at the time when the study took place. Tasos was 46 years old, married, father of one son, living with his family and he had been retired for 20 years. Anna-Maria was 34 years old, she had graduated High School, used to work before the onset of Schizophrenia, was single living with her parents. Martha was 31 years old, single, living with her mother, graduate of High School, and used to work in part-time jobs. Soula was 35 years old, single, and she was living in a mental health community apartment. Vasiliki was 50 years old, married, she was living with her family, used to work before the onset of schizophrenia, and she had elementary school education.



The findings show that the participants did not easily understand the question: "what does quality of life mean to you". The researcher was aware about the difficulties of defining the concept of quality of life, as they are discussed in the relevant literature; therefore, she approached this question by firstly asking the participants: "what does fulfil/satisfy you".

When Alexander was asked: "could you tell me what gives quality to your life", he responded by asking the researcher back the question: "*what do you mean by quality of life?*" The researcher then asked "what does make your life better?" and Alexander answered: "*I haven't thought of such things*". That was a difficult point for the researcher; she went on with the discussion and came back later to ask what Alexander liked the most in his life. When Tasos was asked what was the meaning of quality of life for him he replied: "*no drinks, no being out till late at night, to watch good movies, to listen to good music and our food to be with not much meat*". The researcher felt the need to ask him the same question in another way in order to be sure that Tasos had understood the question. Therefore the next question was: "what gives quality to your life" which seemed to be understandable by the specific participant. Similarly Soula, answered to the question: 'what does quality of life mean to you' by saying; "*no*", moving her head negatively. The researcher had to expand the question as to: "those you mentioned before, about money, job, studies which would fulfill your life, would they also make it better?" and then Soula replied: " *I would certainly feel better...more full, more satisfied*". Finally, Vasiliki found it a "*difficult question*" when she was asked what quality of life meant to her and the researcher had to ask her what would make her

life better, more satisfying. Further on in the discussion she named several aspects of her life which fulfilled and satisfied her.

Another interesting point coming out of the interview experience is that the researcher noted that some participants were talking very fast and they were covering irrelevant issues without having been asked by the researcher to do so. Anna-Maria and Martha were talking fast, they were giving long answers on the questions asked and they were including items, which were not asked in the questions. However, it helped the researcher to go deep into their statements and to explore the meaning of their life experiences which were linked to quality of life. The researcher, due to her psychiatric background knowledge, expected that. According to the International Classification of Diseases-10 (ICD-10, 1993), which represents the European description of mental illnesses, one of the symptoms of patients diagnosed with schizophrenia is the incoherence or irrelevant speech. The researcher had to interrupt the participants when their conversation was unconnected to the question issues and to bring them back to the interview context.

#### 5.1.2 Work and money

Concerning work, seven of the eight participants expressed their willingness to work and they referred to the difficulties they faced in order to find a job, or to maintain a job. They also linked work and money. The eighth participant, Alexander, had never worked in his life and he did not wish to work.

Maria referred to her difficulty to find a job by saying: *"Nobody wants to hire a sick person. They are afraid that we will make problems at work. They*

*prefer the healthy people. In the beginning of my illness, I couldn't do anything, I couldn't work. Now I am better and I would like to work". It is interesting to note what Maria said about the kind of work she would like to have: "...not in the private sector but in the civil service... to be sure that they will not fire me, to be secure". Maria would like to get a job in the civil sector because of the life long contract when working in the civil service in Greece. Therefore she would "be secure". Maria emphasized also the lack of money and the meaning of it into her life by saying: "it is hard to live with the social allowance only, I cannot afford to buy the things I need. Each visit to my son costs me 50 to 60 euros. The social allowance is the only income I have, and I have my expenses for my cigarettes" and she went on to explain how she was feeling about it: "most of the days I go to the church and get lunch there... I do not have enough money to get my food every day... I feel shame that I cannot work to get my own money and to live". Due to her low financial status Maria couldn't afford a place to live as she would like it to be: "...now I live in a small room with a toilet and a small kitchen because I have no money to rent an apartment".*

Michael, who used to work till he became ill, perceived work as very important aspect in his life. When asked if he would like to work, he said that he would like to work because: *"...I like working, I would have an occupation and money, and company, everything..."*.

Referring to work, Tasos said: *"I lost my job because I was under medication"* and he expressed his willingness to have a job in order to earn money.

Anna-Maria who had been out of work since she got sick said: *"I have the specialization in sewing, but I cannot work because I am not productive due to my health problem, it doesn't help me to work outside, they want high productivity".* She went on to explain: *"now I am slow, I cannot do my work fast... It gets me tired and I cannot go on"*. Anna-Maria linked the importance of having a job with money and social relationships and she explained: *"Most people have their jobs and socialize, they talk about common interests, I cannot say anything interesting about my job, only about my activities in the centre; they have something new to discuss every day, and they earn good money, while I take the social allowance which is not enough either for me or to contribute financially at home. They take a lot more and they can do what they want, while I cannot"*. She also mentioned what she would do if she had money: *"...I would deposit it to buy a house for me, to buy clothes which make me beautiful and to go out and have fun, to keep some for the future"*.

Martha used to work in a delivery company after she became ill. She referred to her work by saying: *"I take only the social allowance which is very few money, so I started working once a week and then twice a week and finally every day in a courier company. I had to walk 3 to 4 hours every day and my salary was 16 euros every day. It was not legal, because I was not supposed to have a job while being under the social allowance system. Therefore, I had to lie that I do not work and to take the social allowance, so the system makes you a liar. Now I come to the centre and I work part-time"*. Martha provided another aspect concerning her working experience relevant to the employer's attitude towards patients diagnosed with schizophrenia by

saying: *"...my boss didn't know that I am sick, but then she knew it. People change when they know that you are mentally sick"*

In the same way Soula referred to her willingness to work by stating: *"I would like to get a job... to keep me busy and to improve my financial status. The social allowance is not enough"*.

Vasiliki was working in the Lotos shop which is under the supervision of the mental community centre. Concerning working she said; *"I would like to work outside (she means out of Lotos), but I do not manage it. Whenever I got a job out, I had relapses. Working for nine hours is too much. We, who take medications, are getting tired"*. Vasiliki used to work in several jobs but she found it exhausting and she couldn't keep the jobs. It has to be mentioned that for all the seven participants, money appeared to be an important quality of life indicator. They referred to their willingness to work in order to earn money and to cover their needs.

The findings of the first phase of the current study revealed the aspect of work to be identified as an important contributor to the participants' quality of life. These findings are consistent with the findings from relevant studies. Mowbray et al. (1995) found that symptom exacerbations and rehospitalizations have a negative effect on employment for the patients diagnosed with schizophrenia. Similarly, Lysaker and Bell (1995) found a relationship between negative symptoms of schizophrenia and poor work among the 50 male participants of their study. Priebe et al (1998) explored the attitudes towards work of 24 patients diagnosed with schizophrenia (12 employed and 12 unemployed) in three cities: Boulder, Colorado, United States; Berlin, Germany; and Berne, Switzerland. The participants were likely

to stress the importance of work. The employed ones displayed less psychopathology and significant advantages in terms of objective and subjective measures of income and well-being. The authors concluded that work was associated with a better quality of life for people with schizophrenia. Cook and Razzano (2000) reviewed the literature for relevant publications in the years from 1989 till 1999. According to the collected data only very few patients diagnosed with schizophrenia were employed. Causes for the unemployment of the majority of the patients diagnosed with schizophrenia in the reviewed studies, included high levels of schizophrenic symptomatology, social skills deficits, and neuropsychological deficits. Similar results came out of the study of Gaite et al (2002). The authors compared subjective quality of life and objective quality of life indicators in 404 patients with schizophrenia from five European sites: Amsterdam, Copenhagen, London, Santander and Verona. The results showed that apart from the country's characteristics patients diagnosed with schizophrenia perceived better quality of life when they were working. More recently, Rosenheck et al (2006) examined correlates of employment in a group of more than 1,400 patients diagnosed with schizophrenia. Data suggested that overall employment may be impeded by clinical problems, such as symptoms of schizophrenia and poor neurocognitive and intrapsychic functioning.

### 5.1.3 Family

The interviews with the eight participants of the current study reflected the strong relationship Greek people have with their families. This is one special cultural aspect for the Greek population. Greek people have strong

ties with their family members and they expect their family to take care of them when needed. Therefore, all the participants except one either lived with their families or expressed the wish to have better relationships with them. Alexander was living with his mother despite his age (42 years old) and Martha who was 31 years old was also living with her mother. Anna-Maria named as a quality of life the fact that she was living with her father. Michael was living alone and his sister was doing the house cleaning for him. Tasos was living with his wife and his 22-year-old son. He did not refer to any issues concerning his family except the fact that he would like to have more kids. Similarly, Vasiliki did not mention much about her family; she was living with her husband and one daughter. However, she mentioned that she keeps good relations with other relatives and that she liked to knit things for her family. Among the eight participants, it was only one who was living out of her family and she said that she keeps *"just the necessary"* contacts with her family.

Maria had a sister and when she was asked about the relationships with her, her answer made it clear that Maria was expecting her sister to help her: *"I have no relationships; I just take my niece to the school sometimes. I have no help from my sister"*. When Maria was asked how she was feeling about having no relationship with her sister she just said: *"sad"*. Family was an aspect of quality of life for Maria and she defined quality of life as: *"my son, to be married, to have family, to have a normal house. In the family to be the husband who works and the wife who takes care of the kid, to have money"*. Referring to her 5 year old son, Maria said: *"he is my first priority in my life. He fulfills my life"*, even if she is not taking care of him due to her illness.

A search of the relevant literature revealed family interventions to be effective in reducing exacerbations in schizophrenia; some also improve patients' diagnosed with schizophrenia social functioning and reduce family burden (Glynn et al, 2006; Fischer et al, 2002; Crane-Ross et al, 2000; Hatfield et al, 1996; McFarlane et al, 1995). The focus of the family interventions is based on the education of the family members in living with the family member who is suffering from schizophrenia. Regardless of their origins, these interventions share a number of common features, such as showing empathy for all participants, providing knowledge about the illness, and teaching communication and problem-solving skills (Glynn et al, 2006). Following the programme of the deinstitutionalisation of the patients diagnosed with schizophrenia in Greece, the mental health community centres started educating the family members who live with the patients diagnosed with schizophrenia and special behavioural and psychological courses were initiated for the family support (Karastergiou et al, 2006). Francis and Papageorgiou (2004) compared seven Greek to nine Anglo-Saxon relatives of patients diagnosed with schizophrenia in relation to their expressed emotions. Expressed emotion refers to family communication and interaction patterns such as criticism, hostility and emotional overinvolvement and has proven to be a valuable predictor of the course and outcome of schizophrenia. The findings showed that the Greeks were more intrusive and emotionally overinvolved in their relatives' life compared to the Anglo-Saxons. Greek families also showed stronger behaviour control, which according to the authors, may reflect cultural differences in family structure. Barbato and D'Avanzo (2000) in their review of 25 studies on family intervention in



schizophrenia found that the effect on relapse was well assessed. However, the authors concluded that it remained unclear whether the effect depended on family treatment or on more intensive care and that the failure to relate outcomes to family-mediating variables is a challenge to the rationale underlying family interventions.

#### **5.1.4 Social Functioning, Health, and Psychological Functioning**

The aspect of socializing in patients diagnosed with schizophrenia has been approached in the relevant literature in relation to symptoms and stigma due to the specific illness. Symptoms refer to the negative and positive symptoms of the illness of schizophrenia (as previously described). Stigma refers to the view that persons with mental illness are seen, the way they receive attributes of undesirable characteristics, or deserve reproach because of their mental illness (Corrigan and Penn 1999). Stigma is associated with psychological functioning as was revealed from the data of the current study. Therefore, the domains of social functioning, health, and psychological functioning will be discussed together, as below.

The interviews in the current study revealed social functioning to be related to the participants' quality of life. All the informants reported that they would like to have more social activities, to be with other people, and to exercise their hobbies. It is interesting to note that most of the participants combined their difficulty of socializing with either the perception of others' towards their illness, or their inability to socialize due to their illness and their low income. At this point it has to be noted that the main socializing activities and friends of the participants were from the same mental health centre,

where the participants were followed up. Therefore, those subjects who were participating in the centre's workshops and activities were satisfied with the environment and the relationships they had there. One participant took the chance to ask the interviewer to mediate for her to the centre's authorities in order to include her into the workshops. The researcher was familiar with such unexpected behaviours and she knew how to handle the participant's request, by clarifying her role as a researcher and by reminding the participant that for such items she could talk to the charge nurse who knew the exact rules and procedures.

Maria's answer to the question: "what fulfils you the most" showed how much her friends meant to her: *"to be with other people... it gives me life. I feel alive; I like to be with other people, to talk with them"*. Maria expressed her wish to participate in the workshop programmes of the centre in order: *"to be with the others, to talk with them, to spend sometime with them and to get out of my routine... I miss the company of other people"*. When Maria was asked if she would like to have more friends, she provided an answer along with an explanation on why she could not have friends: *"I would like to have many friends, to go out for a walk, to exchange visits. I like to socialize but it is not easy. After they see that I am sick, they do not want my company. I do not understand why... they prefer the healthy people... maybe they do not want me because I am fat. I want to lose weight, it is a side effect of the medication, I will make it."* Maria referred to "healthy people" in order to differentiate herself as an ill person and she also expressed her feeling of being different due to her illness, therefore, according to her, the others did not want her.

Michael was living alone and when asked to describe his daily life he said: *"boredom" and "loneliness"*. When he referred to his unsuccessful effort to run a garage, he said it was *"a catastroph"* which he explained as: *"I am alone, without friends, without anything"*. In the same way with Maria, Michael would like to have friends and said that his friends: *"since I got crazy (he means his psychiatric disorder), they all disappeared"* reflecting his perception on the stigmatisation caused by schizophrenia. Michael linked money with his social activities. He said that if he had money he would travel around the world: *"I would go around the world... I like travelling"*.

Tasos said that he liked listening to the Greek music much, to watch movies and to hike. He also said that he was used to spend a couple of hours in the cafeteria every day, where he meets his friends. If there were something to change, he would like: *"not to be alone for many hours, to have my wife at home to go together to the cafeteria, to have a coffee, to smoke a cigarette, to talk together, I like this"*. Tasos could not go hiking any more and he said: *"I used to be active, to climb the mountains, now I cannot... My thinking has changed... I do not want to go hiking, I am getting scared by the bad weather. Last time we went, we had to come back due to the heavy snow and the people in the village were laughing at us and calling us "crazy"."* Tasos expressed his interest in going to the theatre but he couldn't afford it: *"I want to go to the theatre and it costs 2,000 drachmas and I cannot go. I want to attend a concert at the House of Music, where they play very nice concerts and I cannot go. The other days there was a movie with orchestra music, the ticket was 2,000 drachmas and I couldn't go"*. Concerning his illness, Tasos said: *"if I hadn't been sick, I would have had a dozen of kids..."*

Anna-Maria was very specific when she referred to the meaning the workshops had for her socializing: *"...I like it because I feel that I am not alone, that I belong to somewhere, that I have some ones who could help me, so when I come here I do not feel alone, there are persons here who can help me when I need them. It is an occupation and an institute at the same time. It fulfills me..."* She went on to distinguish friends and company by saying: *"I like the guys I see, the friends I have, we are all sick and this is common for all of us, I have company because I cannot have friends..."* Anna-Maria mentioned her relationship with her boyfriend and she perceived it as: *"... he is like a present for me, now I have a friend... I feel happy, happy with him, we go out ... during the weekends we go out ..."* Anna-Maria expressed her thoughts on the effect of her illness in her life. She said: *"prior to my sickness, I was different, much different. In the past I was flying... I was a normal person, a productive person, like a healthy person. Not even this I can be now that I am sick, not even normal..."* and she went on to say about her perceptions on other people's attitudes towards her illness: *"I am not in their society very much, I am a bit out of their society... they see that there is something wrong going on with me and then they avoid me and me as their company. I have met quite a few people who do not want me as their company... after sometime they understand that I have a problem, because I cannot talk with them about my interests, their interests"*

Martha referred to the importance of having friends and responded to the question: "what fulfills you?" by saying: *"my relationships with my girlfriends and with the other sex"* and she went on to say: *"it fulfills me to meet people, when I go to get a coffee..."* Martha referred to her illness by

saying: "...she (her friend) doesn't know that I am sick, she wants to be a psychologist and I think that she understands that I am sick; I do not know when I will find the right moment to tell her that I am sick because it makes me feel uncomfortable; you know then questions start like: what are you doing there? where do you work? and so on..." and she went on to clearly describe how she viewed other's opinion about her illness: "...when you tell them that you have a problem, it is like a glass frame stands in between you and them, the handicapped may have a body part missing, with us it is something that is not visible... people change when they know that you are mentally sick...."

In the same way, Soula felt fulfilled by having her friends to talk with and to go out for walks. However, she referred to her illness by implying having coped with it as she said: "in the beginning it was difficult to admit that I am sick, then I got used, now it doesn't bother me".

Working in the Lotos shop was appointed as very important for Vasiliki and she said: "I haven't thought of my life without Lotos because I do not know what I would do, the whole day at home... I do not know what I would do... we have a company with the girls, we talk, we work, we take our time together..." Vasiliki linked some difficulties she was facing in her daily life with her illness. She said: "we, who take medications, are getting tired... physically and then it comes... the relapse..."

Concerning their health status, the participants had realised that the side effects of their medication negatively affect their quality of life. Alexander was the only one showed to be happy taking medication. All the other seven subjects mentioned the impact of medication in their daily life. Martha was worried about gaining weight, Anna-Maria was not feeling active, and she was

socializing less due her medication. Vasiliki and Michael were experiencing having less power to do things they used to do before being sick and Tasos did not feel like hiking after he became ill. Her sickness, caused Maria to be separated from her five old year son, therefore she refers to him as the “*first priority in my life*”. It is also interesting to note the way Martha and Anna-Mara referred to healthy people. They named them “*logical*”, they differentiated themselves from the “*healthy*” ones, and they perceived that there are two different worlds: the healthy and the sick. Moreover, Martha named the “*healthy*” world as a “*ghetto*” which indicates the stigmatisation of patients diagnosed with schizophrenia, as it was perceived by her. These findings support Haghighat’s (2001) statement that the mentally ill people are held more responsible for their disorders than people with other disabilities, resulting in poor self-esteem and demoralisation.

The findings on social functioning and health are in agreement with other findings found in the relevant literature. Crisp et al (2000) interviewed 1790 of the British adult population to determine their opinions concerning those with mental illness. Negative opinions about the mentally ill people were expressed by the participants contributing to mentally ill people’s social isolation, distress, and difficulties in taking social roles. Dickerson et al (2002) studied 74 patients’ diagnosed with schizophrenia experiences on stigma. The authors found that all but one participant indicated having at least one stigma experience. The findings showed that 70% of the participants had been viewed unfavourably due to their mental illness while 55% of them had heard offensive statements. Angell and Test (2002) examined the clinical and situational contributors to social functioning in people with schizophrenia.

Participants were 87 young adults, aged from 18 to 30, with schizophrenia. Data from two time points, 6 months apart, were used to test models predicting five social outcomes: network size, network reciprocity, sociosexual contact, satisfaction with social relationships, and loneliness. Results indicated that an increase in positive symptoms over a 6-month period was associated with the loss of social network ties, a lessening of satisfaction with social relationships, and an increase in loneliness. Similar results were revealed by Schulze and Angermeyer (2003). The authors explored stigma from the subjective perspective of patients diagnosed with schizophrenia by employing a focus group study. Results showed that schizophrenia lead to reduction of social contacts, patients were ignored by neighbours and friends, they were experiencing discrimination, they wished to conceal their illness from friends and relatives, and they were hardly capable of meeting the criteria for social recognition and integration. The findings on social network and loneliness are in agreement with those of the first phase of the current study.

More recently, Ertugrul and Ulu (2004) examined the relation of stigma and symptoms in 60 patients diagnosed with schizophrenia. The results showed that patients who reported to perceive stigmatisation had more severe symptoms than the patients who did not perceive stigmatisation. Positive symptoms and general psychopathology scores were significantly higher in the group perceiving stigmatisation. Patients reporting stigmatisation were significantly more disabled than the group negative for perceived stigmatization. The authors concluded that the relation between perception of stigmatisation and symptoms of schizophrenia is a vicious circle in which the

elements reinforce each other (Ertugrul and Ulu, 2004). The researcher of the current study noted that the life domains, as revealed through out the data analysis of the interviews reinforce each other. The five life domains as identified by the participants and which contribute to their quality of life are interlinked one another. The participants' health condition keeps them away from working, which leads them to having less money for their needs, leading in turn to the influence of their social needs and their image as perceived by the Greek community, according to the Greek culture. Without work and money and due to the stigma accompanying their illness, the participants experienced low social functioning and they became more attached to their families. In the Tables below the indicators of quality of life are listed first (Table 5) and then their categorisation appears in themes (Tables 6 and 7) followed by the concept clarification of quality of life (Table 8). Raw data as was revealed from the interviews was listed as it was expressed by the participants (Table 6). The next step was to generate categories which were related to the meaning of each quality of life indicator as they were expressed by the participants. Burnard (1991) stated that the raw data should be presented and the category systems should be generated independently. Two nurses who were working to the specific community mental health center were invited to also categorise the data. Due to time constraints of the two nurses, the researcher presented the data following the preliminary analysis of the data into the initial categories (Table 7). The two nurses and the researcher independently re-analysed the data into the final categories (Table 8 and Table 9). However, there was debate between the researcher and the two nurses before the final categories were agreed upon. This shows that the



two nurses had not been wholly biased by the initial categorisation made by the researcher. The inter-rated reliability between the researcher and the two nurses was good with a 1.5% discrepancy; therefore, consensus of analysis was confirmed.

**Table 6**  
**Raw data for quality of life indicators**

To be with other people	To talk with other people
To visit son	To cover daily expenses
Feeling shame for getting lunch for "the poor people"	To be able to work
Not to be sick	Spend time with other people
Participate in the centre's programme	Not to have the side effects of the medication
To socialize	To have money
To lose weight	To buy things for self and son
To have good relationships with sister	To live in a good house/apartment
To have a job	To have a partner
To have friends	Travelling
To be loved/cared	Music
Not to be alone	Hiking
Watching movies	No drinks

Family, children, son	To be productive
To make people laugh	To be healthy
To own a house	To buy clothes
To go out and enjoy self	To create
To come to the community centre	Boyfriend
To meet people	Relationship with the other sex
To read books	Not to take medications
To be respected by other people	To help the family
To have money to spend for self and family	The others to accept the sick people
To take care of family	Visit friends
To be perceived as "normal" person	Knit
Father	Sew
To paint	To go out for walks
To go out with friends or cousins	To study computers and foreign languages
To go to the theatre	To go to the cafeteria
To spend time with wife	Get out of the routine
To be married	To have family

To have many children	To take care of the child
To have a permanent job	To be active
To go out with wife	To attend concerts
To keep self busy	The others not to avoid my company

**Table 7**  
**Categorization into themes**

<b>Money</b>	<p>To have money</p> <p>To have money to spend for self and family</p> <p>To buy things for self and son</p> <p>To cover daily expenses</p> <p>To buy clothes</p>
<b>Socializing</b>	<p>To socialize</p> <p>To be perceived as "normal" person</p> <p>To go to the cafeteria</p> <p>To make people laugh</p> <p>To go out and enjoy self</p> <p>To meet people</p> <p>To be with other people</p> <p>To talk with other people</p> <p>To come to the community centre</p> <p>Participate in the centre's programme</p>
<b>Friends</b>	<p>To go out with friends or cousins</p> <p>Visit friends</p>

	To have friends Spend time with other people To have a partner
Family	To be married To have family To have many children To take care of the child To spend time with wife Father Son Family, children To have good relationships with sister To visit son To take care of the family To help the family
Home	To own a house To live in a good house/apartment
Work	To have a permanent job To create To have a job To be able to work To be productive To keep self busy
Hobbies	To go to the theatre To paint To attend concerts Knit Sew To read books Watching movies To study computers and foreign

	languages Travelling Music Hiking
Own self	To be active Get out of the routine To go out for walks Feeling shame for getting lunch for the poor people
Emotional	To be loved/cared The others not to avoid my company
Health	Not to be sick Not to have the side effects of the medication No drinks To lose weight Not to take medications To be healthy The others to accept the sick people

**Table 8**  
**Clarification of the concept Quality of Life**

Work/Money	To have a permanent job To have a job To be able to work To be productive To keep self busy To create To own a house
------------	--

	<p>To live in a good house/apartment</p> <p>To have money</p> <p>To have money to spend for self and family</p> <p>To buy things for self and son</p> <p>To cover daily expenses</p> <p>To buy clothes</p>
Family	<p>To be married</p> <p>To have family</p> <p>To have many children</p> <p>To take care of the child</p> <p>To spend time with wife</p> <p>Father</p> <p>Son</p> <p>Family, children</p> <p>To have good relationships with sister</p> <p>To visit son</p> <p>To take care of the family</p> <p>To help the family</p> <p>To have a partner</p>
Social	<p>To socialize</p> <p>To go to the cafeteria</p> <p>To make people laugh</p> <p>To go out and enjoy self</p> <p>To meet people</p> <p>To be with other people</p> <p>To talk with other people</p> <p>To come to the community centre</p> <p>Participate in the centre's programme</p> <p>Not to be alone</p>

	<p>Boyfriend</p> <p>Relationship with the other sex</p> <p>To go out with wife</p> <p>To go out with friends or cousins</p> <p>Visit friends</p> <p>To have friends</p> <p>To have friends</p> <p>Spend time with other people</p> <p>Get out of the routine</p> <p>To go out for walks</p> <p>To go to the theatre</p> <p>To paint</p> <p>To attend concerts</p> <p>Knit</p> <p>Sew</p> <p>To read books</p> <p>Watching movies</p> <p>To study computers and foreign languages</p> <p>Travelling</p> <p>Music</p> <p>Hiking</p>
Health	<p>Not to be sick</p> <p>Not to have the side effects of the medication</p> <p>To be active</p> <p>No drinks</p> <p>Not to take medications</p> <p>To be healthy</p> <p>To lose weight</p>
Psychological	<p>To be loved/cared</p> <p>Feeling shame for getting lunch for</p>

	<p>the poor people</p> <p>The others to accept the sick people</p> <p>To be perceived as "normal" person</p> <p>To be respected by other people</p> <p>The others not to avoid my company</p>
--	---

The analysis of the qualitative data identified five indicators or domains of quality of life, as experienced by the eight participants, who had been interviewed. The five domains of quality of life constitute the concept clarification of quality of life as it was given by the informants and are listed below, in Table 9.

**Table 9**  
**Quality of life concept clarification**

Quality of Life	Work/Money
	Family
	Social
	Health
	Psychological



## **CHAPTER SIX**

### **METHODOLOGY PHASE TWO**

#### **6.1 Process of Phase Two**

##### **6.1.1 Choosing the appropriate quality of life questionnaire**

Having identified the meaning of quality of life from the patients' perspective in the first phase, the researcher reviewed a number of existing quality of life instruments in order to assess their suitability for the second phase of the study. The researcher identified two main criteria for the selection of the appropriate tool. First the tool should reflect the main domains of quality of life as they emerged from the interviews in the first phase of the study and second it should be easy to understand and fill in by the participants and not to be a complicated tool. Furthermore, it would be an asset, if the instrument was written in Greek, since this is the first official language spoken in Greece. The researcher was aware that only a few participants had participated in a quantitative research study in the past, while for most of them it was the first time to fill in a questionnaire. In order to find the appropriate quality of life quantitative tool, the researcher reviewed the most commonly used quality of life questionnaires in the mental health area as well as the existing tools, which have been translated in Greek and have been used for patients diagnosed with schizophrenia. The intention was not to construct a new tool in order to measure the quality of life for patients diagnosed with schizophrenia living in the community in Greece, but rather to

use an existing quality of life tool. Therefore, the most commonly used quality of life instruments were reviewed.

During the 1980s, the concept of quality of life was introduced in psychiatry and subjective approaches were developed such as the Lehman Quality of Life Interview (QOLI) (Lehman, 1983). More recently other instruments developed in that tradition such as the Lancashire Quality of Life Profile (LQoLP) (Oliver et al, 1996) and the Self-report Quality of Life Measure for people with schizophrenia (Wilkinson et al, 2000). However, generic Health Related Quality of Life (HRQoL) questionnaires like the Medical Outcome Study Short Form-36 Health Survey (Ware and Sherbourne, 1992) recently became of use in studies with chronic psychiatric patients (Meijer, 2002). The National Centre for Health Outcomes Development reported the results of their review on multi-dimensional measures relating to functioning or quality of life in the mental health area (Report to the UK Department of Health, 2000). A total of 85 instruments were identified and many of them were found to be lengthy and time intensive. The Report emphasises that the majority of the instruments are suitable for use in either research or clinical mental health practice. For the purposes of the current study and due to the time limits, it was not possible for the researcher to review all the 85 above mentioned instruments. Therefore, the researcher reviewed four of the widely used quality of life instruments in order to clarify her choice of tool for use in the second phase of the study. The four instruments were selected for review because, according to the researcher, they include most of the quality of life indicators as they had been revealed from the first phase of this study. That was the main criterion while selecting the four instruments. The reviewed tools

are: the Lehman Quality of Life Interview, the Lancashire Quality of Life Profile, the Medical Outcome Study Short Form-36 Health Survey, and the Subjective Quality of Life Profile.

### **6.1.2 Lehman Quality of Life Interview**

Lehman's Quality of Life Interview is a structured self-report interview developed after a national American survey on quality of life. It has been used almost exclusively with psychiatric patients and it consists of 143 items, and it takes approximately 45 minutes to administer (Lehman, 1983). The QOLI measures objective and subjective quality of life in eight life domains: living situation, daily activities and functioning, family relations, social relations, finances, work and school, legal and safety issues, and health. Internal consistency reliability has been tested and re-tested and assessed as good. Construct and predictive validity have also been assessed as good by factor analysis. The QOLI has been used with hospitalized patients as well as with patients living in the community, both in the USA and the UK (Lehman et al, 1986; Simpson et al, 1989). Furthermore it has been used to compare life satisfaction among severely mentally ill patients and general population (Lehman et al, 1982).

Zissi et al (1998) carried out a cross – sectional study in order to measure the quality of life of patients diagnosed with schizophrenia who had moved from Greek hospital settings to Greek community hostels. One of the quality of life questionnaires which was used by Zissi et al was the translated Greek version of the Lehman Quality of Life Interview. The researcher attempted contact with the researcher mentioned above, in order to get the

translated questionnaire and permission for potential use, in case it would be appropriate for the current study. However, the contact was not successful and the original Lehman Quality of Life Interview tool was reviewed in its original version.

### 6.1.3 The Lancashire Quality of Life Profile

The Lancashire Quality of Life Profile (LQoLP) (Oliver et al, 1996) was developed from Lehman's Quality of Life Interview and combines objective and subjective measures in several life domains. It is a structured interview especially developed for people with serious mental illness and based on the patient's self report on specific life domains. Life satisfaction is rated on a 7 point Likert scale, ranging from "can't be worse" to "can't be better". An overall score of the patient's total quality of life may also be obtained. The LQoLP has been tested for reliability (Hansson et al, 1998) and validity (Oliver et al, 1997). In their study Gaite et al (2000) showed that the Lancashire Quality of Life Profile - European Version is a useful instrument, which satisfies the requirements of a good quality of life measure in different European settings. The total score has good internal consistency and reliability, and is similar across sites, although some subscales, especially work, appear to be less satisfactory from the point of view of consistency. However, Andrew et al (1994) reported fair to good validity and weak test-retest scores while Hansson et al (1998) reported good reliability and internal consistency of the instrument. The LQoLP is available in different languages such as English, Dutch, Danish, Italian, Spanish, and Swedish. Van Nieuwenhuizen et al (1998) employed the LQoLP to examine the psychometric properties of the

specific tool as well as the applicability of an adaptation of the LQoLP in the Netherlands. The authors concluded that the Lancashire Quality of Life Profile is highly functional in clinical practice due to its tight structure. Bengtsson-Tops and Hansson (1999) used the Swedish version of the LQoLP to assess the quality of life in patients diagnosed with schizophrenia living in the community. The authors chose the specific tool because of its well structured form and the ability to combine both subjective and objective domains of life (Bengtsson-Tops and Hansson, 1999). However, Hewitt (2006) addresses problems with conceptual and psychometric properties and states that it takes 45 minutes to one hour to administer it. The life domains included in the LQoLP are: client's general well-being, work/education, leisure/participation, religion, finances, living circumstances, legal and safety, family relations, social relations, health, and self-concept. These life domains are in congruent with the results of the first phase of the current study and the use of the LQoLP became an option for the study.

#### **6.1.4 Medical Outcome Study 36-item Short Form**

The Medical Outcome Study 36-item Short Form (MOS SF-36) was developed by Ware and Sherbourne (1992). The instrument focuses on aspects of QoL and functioning that are directly related to health (Hewitt, 2006). The SF-36 includes one multi-item scale that assesses eight health concepts: 1) limitations in physical activities due to health problems; 2) limitations in social activities due to physical or emotional problems; 3) limitations in usual role activities due to physical health problems; 4) bodily pain; 5) general mental health (psychological distress and well-being); 6)

limitations in usual role activities due to emotional problems; 7) vitality (energy and fatigue); and 8) general health perceptions (Ware and Sherbourne, 1992). The SF-36 is a generic measure of health status that has been validated for 14 years of age and older groups in the US, the UK, and in some non-English-speaking countries (McCallum, 1995). The validity of the SF-36 was tested in the National Centre for Epidemiology and Population Health Record Linkage Study using a sample of 555 respondents to the National Heart Foundation Risk Factor Prevalence Survey in 1989 and they were followed up in 1992. The 8 component scales of the SF-36 showed good discrimination between people with and without health conditions, including those with medical and those with psychiatric types of conditions. The SF-36 was a valid measure of general health status among Australian respondents (McCallum, 1995).

Brazier et al (1992) used the postal survey method to test the acceptability, validity, and reliability of the Short Form 36 health survey questionnaire (SF-36), in two general practices in Sheffield. One thousand nine hundred and eighty patients aged 16-74 years randomly selected. The SF-36 questionnaire was retested on a sub sample of respondents two weeks after the first mailing. The response rate for the SF-36 questionnaire was 83% and the rate of completion for each dimension was over 95%. The reliability of the SF-36 was found high (Cronbach's alpha greater than 0.85, reliability coefficient greater than 0.75 for all dimensions except social functioning as well as the construct validity in terms of distinguishing between groups with expected health differences (Brazier et al, 1992). The authors concluded that the SF-36 is a reliable and valid tool. Furthermore, it should be notable that

the patients' response rate (83%) reflects the high acceptability of the SF-36 by the patients.

In their study Jenkinson et al (1994) examined the validity of the Short Form 36 health survey questionnaire (SF-36) in a large community sample and explored the instrument's internal consistency in groups reporting different levels of ill-health. The response rate was high (72%) and the internal consistency of domains was also found to be high, both for the sample as a whole, and when broken down by specific subgroups. Criterion validity was assessed by comparing scores for the seven multi-item dimensions assessing functional status and well being with the global question too the respondents to evaluate their health 'overall'. The authors concluded that the results provide psychometric evidence for the use of the SF-36 with groups reporting varying extents of ill-health (Jenkinson et al, 1994).

The SF-36 Health Survey Questionnaire has been used widely. Aaronson et al (1992) participated in the International Quality of Life Assessment (IQOLA) Project in order to validate, norm, and document the translations of the SF-36 in up to 15 countries, in which the SF-36 Health Survey Questionnaire had been translated and adopted. Toundas et al (2003) used the SF-36, translated in Greek to assess the health of the personnel of hospitals members of the Network of Health Promoting Hospitals. The aim of the study was to assess the health status and health related quality of life of the personnel of the Hellenic Network of Health Promotion Hospitals. The author concluded that the SF-36 proved to be valid by showing evidence that the instrument measures what was supposed and intended to measure. Meijer et al (2002) used the Lancashire Quality of Life Profile (LQoLP) and the

MOS SF-36 instruments to assess the quality of life of 143 out patients diagnosed with schizophrenia. Results showed satisfying feasibility and reliability for both instruments. The authors concluded that the LQoLP allows suggestions for improvements in mental health care while the SF-36 is suitable for comparisons on health related quality of life with other patient groups.

#### 6.1.5 The Subjective Quality of Life Profile

Reviewing the relevant literature, the researcher became familiar with the French Subjective Quality of Life Profile (SQLP). This tool was designed in 1989 by a French team of researchers who recognized the limitation for the European researchers concerning the fact that most quality of life questionnaires were available in English. Gerin et al (1992) developed the SQLP, a 30 item patient administered questionnaire, to assess quality of life and which can be used in the general medicine as well as in the mental health area reflecting the French language and culture (Dazord et al, 1998). The notion underpinning the development of the SQLP is that the subjective quality of life requires a specific model. The medical approach used to assess quality of life was rejected by Gerin et al because, although suitable to therapeutic trials, it considers only the objective quality of life (Gerin et al, 1992). The model uses the concept of goals in a broad sense and emphasises on the "subjective weight" meaning the way the individual perceives the distance to his/her goals. This subjective weight depends on three factors: the importance of the goal as perceived by the individual, the individual's tolerance of the distance between his/her position and his/her



goals, and the individual's ability to cope with this distance (Gerin et al, 1992). Each main aspect of subjective quality of life is assessed independently and the results are presented in the form of profiles rather than indices. The main characteristics of the questionnaire are:

- Selected items describe the main domains of life and due to their wide use they constitute the core of the questionnaire. Other items can be included or deleted depending on the population under study.
- The same set of questions is applied to all the items of the core of the questionnaire.
- A set of open-ended questions can be included in order to get unforeseen information (Gerin et al, 1992).

The domains of life which are explored through the SQLP are: functional life, referring to ability to move, sexual, sleep and so on; social life, referring to social roles, relationships; material life referring to financial issues, goods, house; and spiritual life referring to the aesthetics, religion, thinking and so on. The measures applied for each one of the life domains and which constitute the same set of questions for the core of the questionnaire are:

- Degree of satisfaction: refers to the degree of satisfaction related to each domain of life and it is a direct measure for the evaluation of what the individual experiences.
- Degree of importance: assesses the subjective importance of one each life domain to the individual him / herself. This assessment identifies the personal values of the individual and any potential

changes due to the treatment or the disease. This measure is useful to explain the level of the subjective quality of life.

- **Expectations for change:** measures the degree of expected changes on the core items. This type of measure can explain the level of satisfaction which depends on corresponding changes. This can also explain potential disappointment in case the effective change does not match to the anticipated change; it can lead to a negative degree of satisfaction (Gerin et al, 1992).

In the SQLP, subjective quality of life is considered in terms of experience (satisfaction/dissatisfaction) as well as in a multidimensional perspective as a set of variables relating to physical and mental functioning, social integration, and relations. The SQLP evaluates changes in quality of life by measuring the degree of satisfaction. While the core questionnaire includes 27 questions, the methodology makes it possible to choose not only the items which are most appropriate for the population under study but also the set of questions to be posed namely: satisfaction, importance, and expectations for change (Chahraoui et al, 2006). The SQLP has been validated in somatic medical studies and in the late nineties has been introduced in the area of psychiatry. It has been found to be highly sensitive and clearly distinguishes between different subject profiles as a function of pathology, sex, and age. The studies indicate satisfactory reliability and an excellent level of acceptance by subjects. More specifically, Gerin et al (1992) validated the SQLP on several sample populations (500-700 individuals). It takes 15 to 20 minutes to answer the listed items. Principal component analysis showed the SQLP assesses health as well as relationships and

interest in the external world. It shows good internal consistency (split-half correlation= 0.93; Cronbach alpha= 0.9 and 0.86). The various types of questions were understood and were not confused. Test-retest correlations were reasonably high and feasibility was very high (94.5% of the participants completed and returned the questionnaires). In 1997, eight years after its development, the SQLP had been validated on more than 3,000 individuals with various illnesses (Dazord, 1997). Internal reliability and structure validity were shown satisfactory. More recently, Dazord (2002) stated that since its development, the SQLP has been endorsed and tested on approximately 14,000 subjects in total, from both physical medicine area and mental health area. The test-retest explored the answers of the questionnaire after some time. The time was specific so the subjects on the one hand had the time to evolve significantly and on the other hand they did not remember their exact answers given by them on the first time filling in the questionnaire. At the same time with the patients, the questionnaire was also filled in by family members and caregivers to clarify its feasibility. The table below shows the populations in which the SQLP has been used (Dazord, 2002).

**Table 10**  
**SQLP Population Applications**

<b>Population Category</b>	<b>Number of sample</b>
Cardiovascular diseases	843
Diabetes	1009
Gastrointestinal diseases	289
Psychiatric disorders	2882
Cancer	695

Geriatrics	141
Others	2599
Healthy population	7826
Adults in the USA	443

**6.1.6 Appropriateness of the reviewed quality of life instruments.**

A comparison of the reviewed tools is provided in the Tables 11a and

11b.

**Table 11a**

**Comparison of the reviewed tools (a)**

<b>Tool</b>	<b>Suitable for assessment of QoL in mental health</b>	<b>Reliability score</b>	<b>Internal Validity</b>	<b>Easy to use</b>
<b>SQLF</b>	Yes	Good	Good	Yes (It takes 15-20 minutes to administer, it is written in a very clear way)
<b>LQoLP</b>	Yes	Fair to good 0.58 to 0.79	Fair to good	Impractical due to its length of administration (45 to 60 minutes to administer)
<b>SF36</b>	Mostly used in pts with chronic somatic illness, as well as for comparisons between different treatments and different sample age groups. It has also been used in the mental health area	Fair to good 0.71 to 0.89	Good	Yes (It takes 10-15 minutes to administer)
<b>Lehman QLI</b>	Yes, exclusively used with persons with severe mental disorders	0.79 to 0.88	Good	It consists of 143 items and requires 45 minutes to administer

**Table 11b**

**Comparison of the reviewed tools (b)**

<b>Tool</b>	<b>Large body of research on tool</b>	<b>Large populations tested with tool</b>	<b>Already used on Greek population</b>	<b>Suitable in Greek culture</b>
<b>SQLF</b>	Yes , mostly in the French research area.	Yes (more than 10000 people)	Yes	Yes (easy to use, reflects items which are understandable and in congruence to the Greek culture)
<b>LQoLP</b>	Yes, Bengtsson-Tops and Hansson, 1999; Priebe et al, 2000; Gaite et al, 2009; Andrew et al, 1994; Ruggeri et al, 2002; Meijer et al 2002	Yes (more than 10000 people)	No	No (too complicated for Greeks)
<b>SF36</b>	Yes, Beusterian et al, 1996; McCabe et al, 1996; Sciolla et al, 2003; Bousquet et al, 1994; Fielder et al, 1996, Lee et al, 1995; Russo et al, 1998; Anderson et al, 1990; Revicki et al, 1999; Brazier et al, 1992; Meijer et al, 2002	Yes (more than 10000 people)	Yes	Yes
<b>Lehman QLI</b>	Yes, Vandiver, 1998; Mubarak et al, 2003; Lehman et al, 1986; Lehman et al, 1991; Lehman et al, 1992; Rosenfield, 1992; Rosenfield and Need-Todd, 1993; Simpson et al, 1989	Yes (more than 10000 people)	Yes	No (It reflects items of the American culture which would not fit to the Greek

Lehman Quality of Life Interview (QOLI) was perceived by the researcher of the current study as a complicated tool. It includes several ways of questioning such as the use of codes, cards, and scales. Furthermore, the QOLI instrument was developed in the 1980's and it could be questioned whether tools developed over 20 years ago would still be applicable and acceptable in the changing society of the 2000's. Moreover, the researcher would prefer to use an original European quality of life instrument, which would fit more to the Greek culture. Knudsen et al (2000) in their article on the cross-cultural adaptation of outcome measurements for schizophrenia stated that internationally standardised and reliable tools should describe patients, services, costs and outcomes across cultural boundaries.

The researcher of the current study was aware that the Medical Outcome Study 36-item Short Form (MOS SF-36) has been one of the most widely used generic Health Related Quality of Life instruments in populations with chronic somatic illness for the last 5 years (Meijer, 2002). Therefore, it is an instrument to measure health related quality of life and it can be used in any patient group. In the mental health area, the SF-36 receives little support concerning the appropriateness for its use. Russo et al (1998) tested the validity and reliability of the SF-36 in outpatients diagnosed with schizophrenia. The SF-36 was shown to have good internal consistency, stability, and concurrent validity. The authors pointed out that the mental health sub scales of the SF-36 had poor discriminant validity, compared with the physical functional scale which demonstrated good discriminant validity. It has to be noted that due to the small size of the sample (n=36), generalisations should not be made. The researcher of the current study did

not use the Greek version of the SF-36 for two reasons. First, the aim of the researcher was not to validate the SF-36 in the mental health care area and specifically in the patients diagnosed with schizophrenia but to employ a questionnaire which reflects the aspect of quality of life as described by the informants in the first phase of the study. Second, Tounda's et al (2003) study had not been published by at the time the current study started taking place (2002), therefore it was not available in case the researcher wanted to review the translated Greek version of the specific tool.

It has been mentioned above that the life domains included in the Lancashire Quality of Life Profile (LQLP) are congruent with the results of the first phase of the current study. However, it was perceived as impractical due to its length of administration (45 to 60 minutes to administer).

Subjective Quality of Life Profile's (SQLP) appropriateness was based upon not only the congruence of the life domains included in the SQLP, but also upon the correlation which is provided between those life domains to the participants' rating of importance, satisfaction, and expectance for change. By using the SQLP, the researcher attempted to measure the "subjective weight" of the life domains which depends on the importance of the goal as perceived by the individual, the individual's tolerance of the distance between his/her position and his/her goals, and the individual's ability to cope with this distance, (Gerin et al, 1992).

The SQLP has been translated in Greek by Damigos and Siafaka in order to be used in renal patients. Damigos is currently a professor in the

department of Psychology in the University of Ioannina, Greece. In early 2002, the researcher of the current study contacted Damigos and received the Greek version of the SQLP as well as approval to use it in her study. The Greek version of the SQLP consists of the 27 core items of the original French SQLP and 22 more items have been added by the Greek researcher Damigos. The questions under each item referring to satisfaction are represented by "a", those referring to importance by "b", and those referring to change by "c". Furthermore, one more question "d" concerning the ability to cope has been added to the original set of three questions under each item. The rest of the questionnaire remained without any other changes from the original version. The researcher employed the original full SQLP version as it was translated in Greek. However, due to the time limitations and the specific time frame of this study the data which derived only from the core domains of the questionnaire were further analysed and used. The data of the remaining questionnaire are available to the researcher for future analysis and discussion. The English version of the SQLP is provided in APPENDIX C.



## **CHAPTER SEVEN**

### **ANALYSIS OF DATA AND FINDINGS PHASE TWO**

#### **7.1. Analysis of the quantitative data**

##### **7.1.1 Demographic characteristics of participants**

Fifty one participants of the sample were female and 50 male. Seventeen had children and 84 did not. All received medication. The profiles for age, years sick and educational level are seen in Figure 1, Figure 2 and Figure 3. It is seen that the sample is almost exactly split by gender, most do not have children, are typically middle-aged, have been sick for up to about forty years, and typically 15-20 years, and are mostly not graduates, but typically have completed secondary education.

Figure 1: Age profile

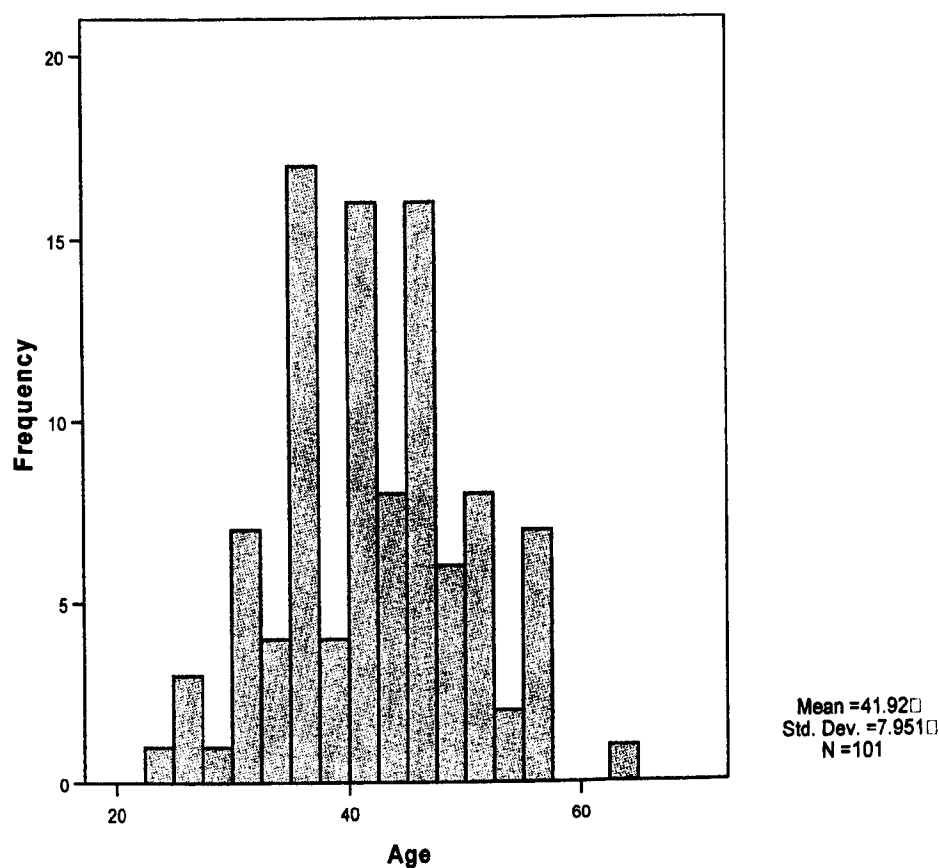
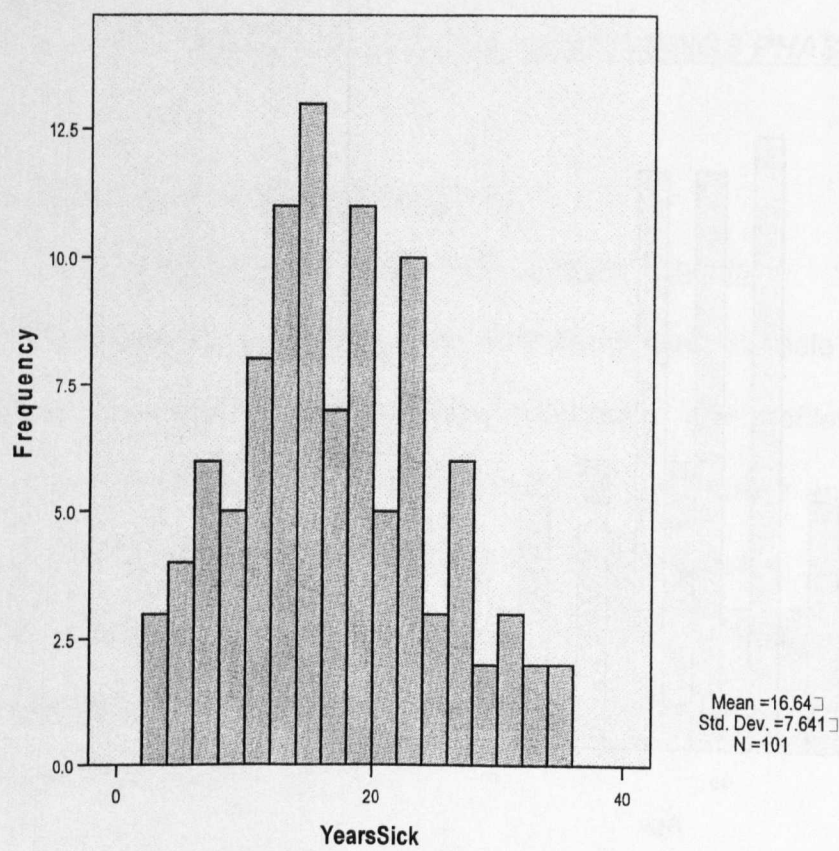
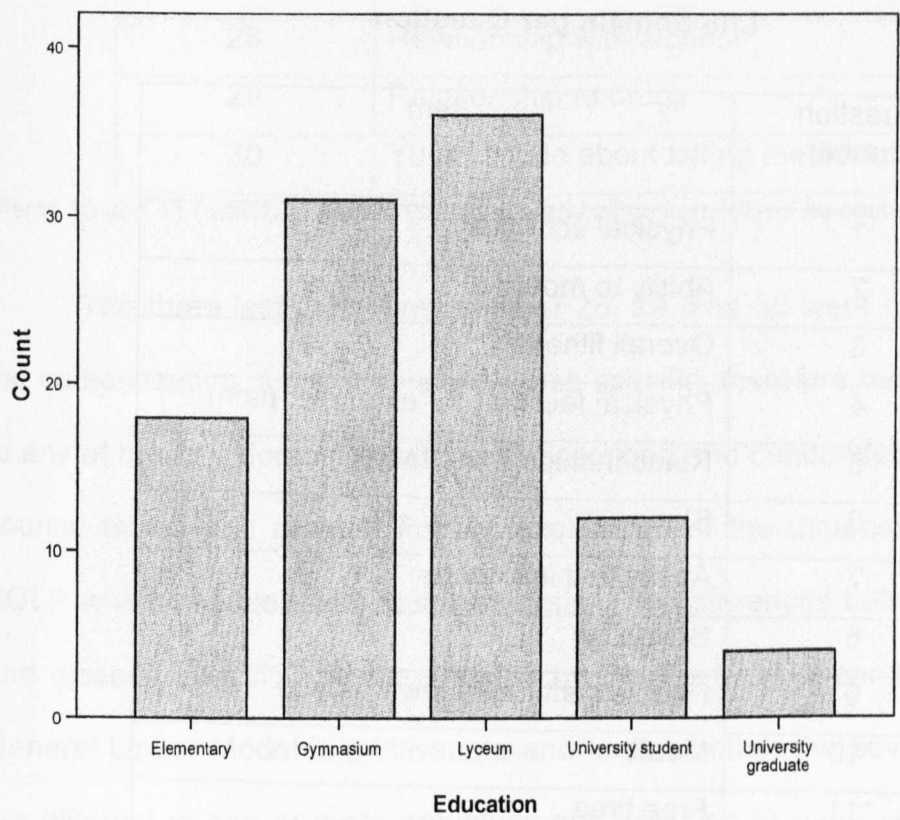


Figure 2: Years of Sickness



**Figure 3: Level of Education**



In SQLP there are stated to be four domains, but in publications seen it is not clear which questions relate to which domain. In practice the SQLP uses all 27 core questions as a profile.

The researcher of the current study categorized the core questions into functional, social, material, and spiritual (Gerin et al, 1992). The researcher's categorization of the questions (Table 9) into the above mentioned domains was in agreement with her supervisor and is shown in Table12.

**Table 12****Life domain per Question**

<b>Question number</b>	<b>Item</b>
1	Physical activities
2	Ability to move
3	Overall fitness
4	Physical feeling ( for example: pain)
5	Relationships with others
6	Sleep
7	Ability to think, focus
8	Sexuality
9	People's attitudes towards you
*10	Meals
*11	Free time
12	Income/money
13	Time with friends
14	Time for professional activities
15	How you feel about yourself
16	Inner self
17	Physical health
18	Relationships with close family or friends
19	Personal activities or leisure time
*20	Participation in group activities
21	Living with someone
22	Material conditions of daily life
23	Physical abilities
24	Feeling free
25	Way you see your future

26	Religious faith
27	World view
28	Relationship with alcohol
29	Relationship to drugs
30	Your attitude about taking medications

\*Items 10 and 11 (material) and 20 (spiritual) could all be considered as social

The three last questions, number 28, 29, and 30 were not included in the categorization, since they are disease specific, therefore they do not refer to any of the four domains. Data were described and condensed using simple counts, tables and graphs. Further exploration of the dimensionality of the SQLP was conducted with factor analysis. The differences between the core and disease specific questions tested by the General Linear Model (GLM). General Linear Model is multivariate and tests whether the several variables are different in one or more groupings and with one or more co-variants. By giving a single p value for many simultaneous tests it removes the type II errors that multiple testing would make more likely. Only where an overall significant p value is found are individual differences even looked at.

**7.2. Descriptive analysis**

The mean value, minimum and maximum values and standard deviations of all 27 core questions and the three disease specific ones are shown in the detailed statistics results in APPENDIX B. The additional question (d), asked “Do you manage to overcome the potential difficulties referring to this topic?” is also included in the descriptive statistics. For the

answers a (satisfaction), b (importance) and c (expectation of change) the mean values are shown in Table 13.

**Table 13**  
**Mean Value per question item**

Question number	Item	Mean a (satisfaction)	Mean b (importance)	Mean c (change)
1	Physical activities (Functional)	.25	1.56	.57
2	Ability to move (Functional)	.31	1.61	.63
3	Overall fitness (Functional)	-.10	1.47	.50
4	Physical feeling ( i.e.: pain) (Functional)	.29	1.05	.40
6	Sleep (Functional)	.19	1.47	.62
17	Physical health (Functional)	-.05	1.61	.61
23	Physical abilities (Functional)	-.14	1.43	.48
10	Meals (Material)	1.41	.49	.24
11	Free time (Material)	.11	1.34	.46
12	Income/money (Material)	-.64	1.58	.32
14	Time for professional activities (Material)	-.46	1.36	.22
22	Material conditions of daily life (Material)	-.01	1.25	.38
5	Relationships with others (Social)	0.7	1.45	.53
7	Ability to think, focus (Social)	0.3	1.53	.52

8	Sexuality (Social)	-.22	1.14	.40
9	People's attitudes towards you (Social)	-0.7	1.32	.51
13	Time with friends (Social)	.06	1.22	.41
18	Relationships with close family or friends (Social)	.02	1.65	.36
19	Personal activities or leisure time (Social)	.68	1.03	.32
21	Living with someone (Social)	.08	1.56	.36
15	How you feel about yourself (Spiritual)	-.20	1.38	.58
16	Inner self (Spiritual)	-.14	1.14	.41
20	Participation in group activities (Spiritual)	.73	.93	.23
24	Feeling free (Spiritual)	-.02	1.40	.38
25	Way you see your future (Spiritual)	.31	1.10	.46
26	Religious faith (Spiritual)	.63	1.56	.35
27	World view (Spiritual)	-.10	.61	.23
28	Relationship with alcohol	1.69	.07	0.7
29	Relationship to drugs	-.10	1.40	.22
30	Your attitude about taking medications	-.11	1.57	.41



**Table 14**

**Categorisation of the core questions: (According to the researcher of the current study)**

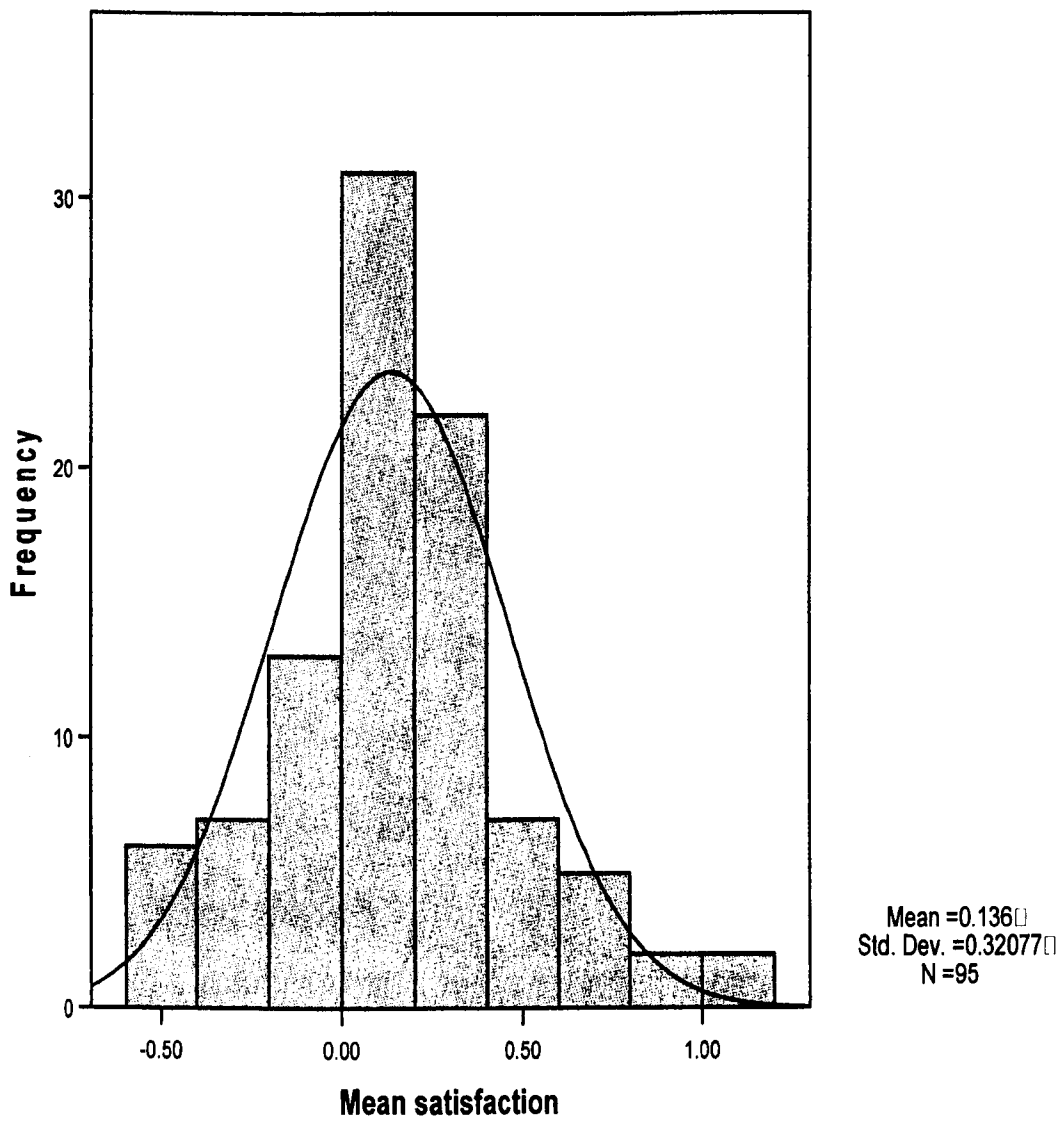
Life Domain	Question Number
Functional	1,2,3,4,6,17,23
Social	5,7,8,9,13,18,19,21
Material	10,11,12,14,22
Spiritual	15,16,20,24,25,26,27

The 27 questions that form the core of SQLP were summed to give three values: the sum of satisfaction for the items, sum of perceived importance of items and sum of expectation of change of items. Means of the 27 questions were also computed for each subject, as it shows in Figure 14, Figure 5 and Figure 6. For all three types of question the responses were more positive than negative. However satisfaction was less than perceived importance or expectation for change.

The findings show that the participants experience an overall satisfaction with the items addressed in the core questions, while only a few are either unsatisfied or very satisfied. No one seems to be extremely unsatisfied (Figure 4). Most of the participants perceive as important (from somewhat to very important) the items under question and only a few scored them as extremely important (Figure 5). Concerning their expectations for

change, most of the subjects seem to be optimistic and very few see no change to the current situation referring to the core questions (Figure 6).

**Figure 4: Mean satisfaction**



**Figure 5: Mean perceived importance**

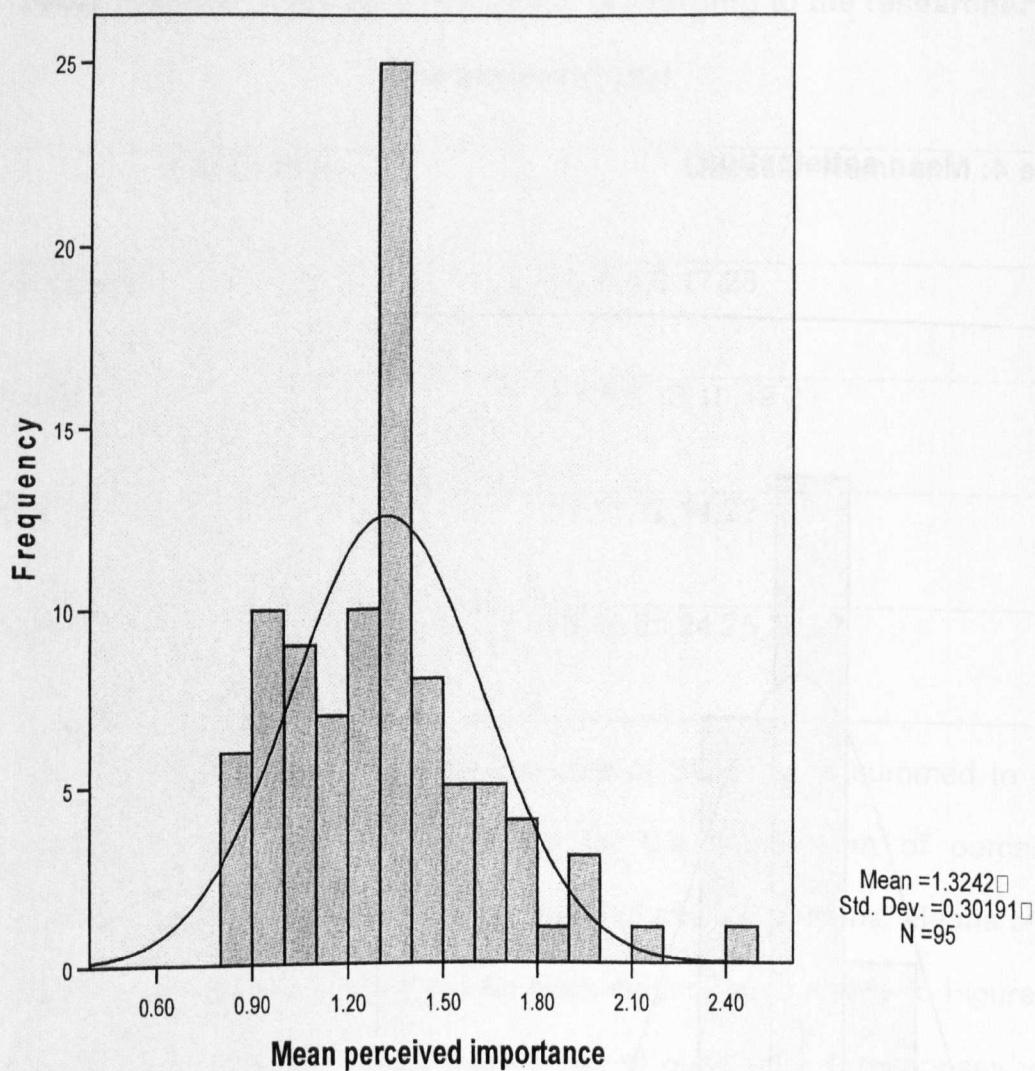
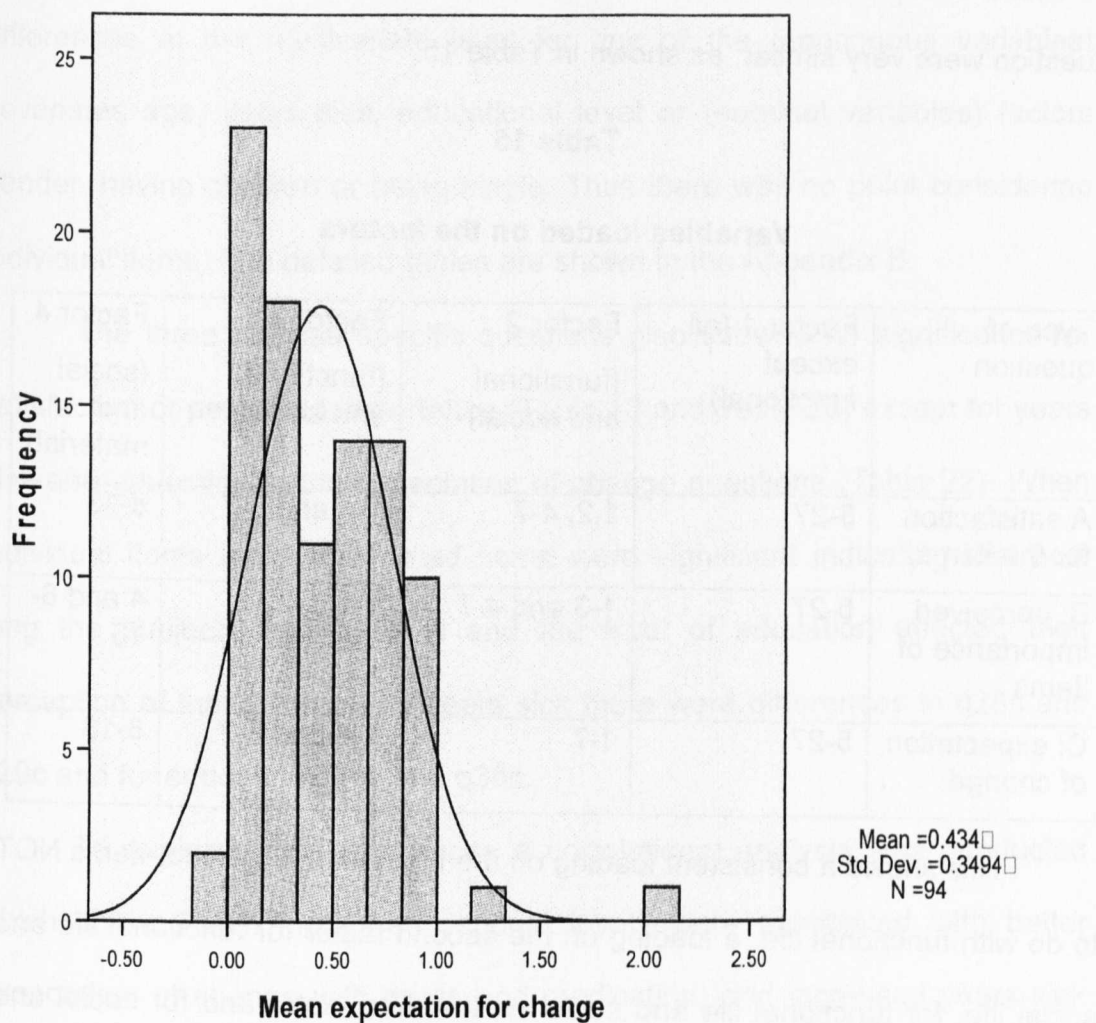


Figure 6: Mean expectation for change



**7.3. Factor analysis**

Factor analysis was conducted separately on the three types of question. For each there were four components that had eigenvalues above one (the Kaiser criterion). While this appeared to confirm the four factors proposed for the tool, the loadings suggest this is not precisely the case. The detailed statistical tables are shown in Table 18 to Table 30 of the APPENDIX

B. These show the variables that loaded on the factors for the three types of question were very similar, as shown in Table 15.

**Table 15**  
**Variables loaded on the factors**

Type of question	Factor 1 (all except functional)	Factor 2 (functional and social)	Factor 3 (functional and social)	Factor 4 (social and material)
A satisfaction for the items,	5-27	1,2, 4-7	1-4 and 5-7	8-13
B: perceived importance of items	5-27	1-3 and 4-7	1-4	4 and 8-13
C: expectation of change	5-27	1-7	1-4 and 5-7	8-13

This shows a consistent loading on the first factor largely for items NOT to do with functional life, a loading on the second factor for functional life and social life, for functional life and social on the third factor and for social and material life on the fourth factor. Thus there are four factors but not precisely those designed to be measured by SQOL. However they are similar: one factor is functional, two and three are combinations of functional and social and the fourth social and material. N.B. spiritual does not load on itself but only with all but functional on the first factor. Thus factor analysis justifies four domains.

#### **7.4 General linear model: Analysis of variance**

For each type (satisfaction, perceived importance and expectation of change) of the core questions a multivariate analysis was conducted

employing GLM (Generalised linear model). These showed no significant differences at the multivariate level for any of the (continuous variables) covariates age, years sick, educational level or (nominal variables) factors gender, having children or being single. Thus there was no point considering individual items. The detailed tables are shown in the Appendix B.

The three disease specific questions also showed no significance for satisfaction or perceived importance (Table 18 and Table 20) except for years sick and education in the expectation of change questions (Table 22). When individual items were considered some were significant indicating that how long the subjects had been ill and the level of education affected their perception of these items. For years sick there were differences in q28c and q29c and for education q29c and q30c.

To explore these differences a correlational analysis was conducted which showed that higher educational levels were associated with better expectation of change with drugs and medication, and increased years sick with more negative expectations of alcohol and drugs (Table 16).

**Table 16**

**Correlations**

			Education	q28c new	q29c new	q30c new	Years Sick
Spearman's rho	Educational	Correlation Coefficient	1.000	.075	.221(*)	.326(**)	.060
		Sig. (2-tailed)	.	.469	.031	.001	.553
		N	101	96	96	96	101
	q28c new	Correlation Coefficient	.075	1.000	.320(**)	-.031	-.300(**)
		Sig. (2-	.469	.	.001	.763	.003

		tailed)					
		N	96	96	96	96	96
	q29c new	Correlation Coefficient	.221(*)	.320(**)	1.000	.207(*)	-.306(**)
		Sig. (2- tailed)	.031	.001	.	.043	.002
		N	96	96	96	96	96
	q30c new	Correlation Coefficient	.326(**)	-.031	.207(*)	1.000	.053
		Sig. (2- tailed)	.001	.763	.043	.	.607
		N	96	96	96	96	96
	Years Sick	Correlation Coefficient	.060	-.300(**)	-.306(**)	.053	1.000
		Sig. (2- tailed)	.553	.003	.002	.607	.
		N	101	96	96	96	101

\* Correlation is significant at the 0.05 level (2-tailed).

\*\* Correlation is significant at the 0.01 level (2-tailed).

## **7.6 Conclusion**

There are four factors in the SQLP, and in part these map onto the domains it is designed to measure.

At the multivariate level there are no differences in this population with respect to age, gender, education, marital status, or years sick in the core questions. For the disease specific questions there are also no significant differences except for the expectation of change where education and years sick were significant. Years sick were negatively correlated with positive expectation and education positively correlated. I.e. subjects who were better educated and/or had less prolonged illness were more positive about the future.

While there are these differences in disease specific questions, these only relate to expectation of change. For the core questions there are no

differences noted for any of the demographic variables. This is consistent with the entire group having a homogeneous view of quality of life. One might argue that people diagnosed with schizophrenia since at least two years and who remain on medication share a similar quality of life. Since the demographic variables would be expected to impact on quality of life, this might mean a suffering from (or being diagnosed with) schizophrenia puts people of different age, gender, having children and marital status at the same level. There is no evidence that educational level or even years of sickness make any difference in quality of life.



## **CHAPTER EIGHT**

### **DISCUSSION PHASE TWO**

#### **8.1 Discussion of Findings**

The aim of the researcher during the second phase of the study was to further expand the research question and to measure the quality of life for patients diagnosed with schizophrenia living in community in Greece, in order to further answer the Research Question: "What is the meaning of quality of life for the patients diagnosed with schizophrenia living in the community in Greece". The domains of life explored by the Subjective Quality of Life Profile were categorised in four categories: functional life, social life, material life, and spiritual life. The discussion of the findings refers to the measurement of the above mentioned four life domain categories under the prism of satisfaction, importance, and expectation for change.

Data revealed that the participants experienced an overall satisfaction with the items under the four categories of life domains. However, negative scores of satisfaction are noted in all the four categories. These findings are consistent with the findings of the study done by Dazord (2002) who used the Subjective Quality of Life Profile to evaluate the quality of life of mostly French populations with several illnesses, including a category with 45 French psychotic patients. The scores of satisfaction in life domains as revealed from the current study and from Dazord's psychotic sample are shown in the Table 16 below:

**Table 17**  
**Scores of Quality of Life domains**

Life Domains (factors)	Current Study Scores of satisfaction	Dazord (2002) Scores of satisfaction
Overall fitness (functional)	-0.10	0.4
Physical health (functional)	-0.05	0.45
Physical abilities (functional)	-0.14	-0.2
Sleep (functional)	0.19	0.7
Income/money (material)	-0.64	0.1
Free time (material)	0.11	0.3
Time for professional activities (material)	-0.46	0.4
Material conditions of daily life (material)	-.01	1.3
Relationships with others (social)	0.7	0.75
Sexuality (social)	-0.22	0.15
People's attitudes towards you (social)	-0.7	0.8
Time with friends (social)	0.06	0.6
Relationships with family or friends (social)	0.02	0.85
Personal activities or leisure time (social)	0.68	0.55
Living with someone (social)	0.08	0.15
Inner self (spiritual)	-0.14	0.65
How you feel about yourself (spiritual)	-0.20	0.4
World view (spiritual)	-0.10	-0.6
Participation in group activities (spiritual)	0.73	0.2

Way you see your future (spiritual)	0.31	0.5
Feeling free (spiritual)	-0.02	0.45

It can be noted that in general there are similar overall scores of satisfaction experienced by both group samples, the Greek and the French ones. However, the participants of the current study experienced the lowest scores of satisfaction in life domains related to their income and money, time with professional activities, sexuality, and their feelings of themselves. A difference is also noted between the scores on material conditions of daily life and feeling free, which appear to be slightly negative for the Greek participants. These differences in the findings could be due to the differences among the two countries in relation to policies concerning mental health and the patients diagnosed with schizophrenia who live in the community as well as cultural differences between Greeks and French populations. The income of the patients diagnosed with schizophrenia in Greece depends on their occupational status before the onset of schizophrenia. For those who have completed certain years of work, the pension is their monthly income. For those who had never worked or are not eligible to get a pension, a welfare benefit is given to them by the government. The welfare benefit or social allowance can be perceived as a basic income which is usually very low to fulfil their material needs. In addition to their low income, the patients diagnosed with schizophrenia in Greece struggle to be employed due to the stigma of their illness, which is related to people's attitudes towards schizophrenia and the people suffering from schizophrenia. This aspect was revealed from the participants of the current study who scored their

satisfaction with "people's attitudes towards you" with slightly negative score (-0.7) while the French sample scored it higher (0.8). In Greece it is taken for granted that patients diagnosed with schizophrenia cannot be employed and they can only perform easy working tasks. Previous studies (Morgan and Gopaldaswamy 1983; Bacani-Oropilla et al, 1991) have concluded that people diagnosed with schizophrenia tend to be in positions involving low levels of interpersonal interaction such as cleaning and labouring. It has to be noted that the difficulty of getting a job was strongly expressed by the participants in the first phase of this study. However, the symptoms of schizophrenia may be a serious reason for considering the employment of the patients diagnosed with schizophrenia (Cook and Razzanno, 2000). The search of the relevant literature revealed that there is no study on the material status of the Greek patients diagnosed with schizophrenia or on their employment. Neither is there a comparison study on this topic between Greece and France. However, Marwaha et al (2007) examined employment patterns in a large representative sample of 1208 people with schizophrenia resident in Germany, France and the UK. It was found that the overall employment rate of participants was 21.5%, but varied between countries and sites, with rates of 12.9% in the UK, 11.5% in France and 30.3% in Germany. The authors concluded that local and national factors towards the employment of patients diagnosed with schizophrenia may include professionals' and patients' attitudes and values regarding the feasibility and importance of work, the attitudes of employers and the public, the stigma patients experience in the labour market, benefits systems and employment law. Another important finding of the study was that similar numbers of participants were living alone in each country, but more

German respondents were living with partners and/or children, and more French respondents with their parents.

Concerning their functional life the participants were found to be less satisfied with their overall fitness, physical health, and physical abilities. These findings are in congruence with the findings of previous studies done on the patients' diagnosed with schizophrenia quality of life. Ritsner (2007) examined whether and how cognition deficit predicts quality of life impairments in patients diagnosed with schizophrenia. The Computerized Cambridge Automated Neuropsychological Test Battery, the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) and the Quality of Life Scale (QLS) were used in 62 patients with chronic schizophrenia. Results showed that deficits in functioning, attention, memory and motor skills were related to the severity of symptoms, emotional distress, and side effects and consequently contributed to quality of life appraisal in schizophrenia. The impact of schizophrenia symptoms was examined by Norman et al (2000) in 128 patients diagnosed with schizophrenia living in the community. The Quality of life Scale, the General Well-Being Scale and Scales for Positive and Negative symptoms were used and results showed significant correlations with all symptom measures and functioning for the total sample. Hansson et al (1998) investigated the prevalence and severity of needs of 119 psychiatric inpatients and outpatients by using the Swedish version of the Camberwell Assessment of Needs instrument. Findings showed that the five most predominant areas of expressed need were psychological distress, psychotic symptoms, physical health, company, and daytime activities.

One significant result of the current study concerns satisfaction with social life issues. The participants experienced as important and showed high satisfaction scores with the life domains referring to their social functioning and these are in congruence with the French participants in the study done by Dazord (2002). Both Greek and French participants were satisfied with their time with friends, relationships with close family or friends, personal activities or leisure time, and living with someone. One possible explanation could be the fact that the participants of the current study were keeping social relations with the other outpatients of the same mental health centre. This is supported by the fact that the informants of the first phase of this study were satisfied having friends from the same mental health centre, even though they all reported the importance of social functioning for them. Findings of relevant studies are in agreement that social relationships is an important quality of life issue for people with schizophrenia but are in conflict with the findings of the current study since they show that patients diagnosed with schizophrenia experience difficulty in the area of their social relationships (Huxley and Warner 1992; Lehman and Steinwachs 1998) and have high rates of loneliness (Brown 1996; Gerstein et al. 1987). Bengtsson-Tops and Hansson (2001) investigated the needs for social network of 120 patients diagnosed with schizophrenia living in the community in Sweden. The participants indicated dissatisfaction with diminished social networks, were not satisfied with their social contacts and stated a need for more social contacts in their daily life, and more friends who would visit their home. The authors concluded that satisfaction with social contacts was positively correlated to a better quality of life and better mental health and the lack of social contacts and

networks could be due to the illnesses symptoms and the stigmatisation of the patients diagnosed with schizophrenia. Similarly, in an American study McDonald and Badger (2002) investigated the experiences of social functioning of people with schizophrenia. The authors concluded that social functioning was critical to the health and quality of life of people with schizophrenia. Angell & Test (2002) compared the social functioning of 84 patients diagnosed with schizophrenia with healthy people and found that they experienced significantly worse social networks than the control subjects and that this was associated with an increase in positive and negative symptoms and decrease in their quality of life.

The findings of low satisfaction with social functioning reflect the influence of stigma on patients diagnosed with schizophrenia in Greece. Moreover, stigmatisation was revealed from the data gained through the interviews during the first phase of the current study. Previous studies on stigma support the heavy stigma attached to mental illness, particularly schizophrenia, by the public which affects patients and their families. Two surveys of neighbours of patients diagnosed with schizophrenia living in sheltered housing in the UK revealed that people were perceiving the patients diagnosed with schizophrenia as difficult to communicate with, unpredictable, and dangerous. Moreover, people were confusing mental illness with learning difficulties ( Leff, 1998). Attitudes of the urban population in Germany towards people with mental illness were investigated by Gaebel et al (2002). A total of 7,246 Germans were asked about their knowledge in regard to schizophrenia, their social distance from people with schizophrenia and estimations of the social stigmatisation of mental patients in general. The majority of the

participants believed that people with schizophrenia often or very often need prescription drugs to control their symptoms and characterized patients diagnosed with schizophrenia as unpredictable and with strange behaviour.

Another social factor with lower scores for satisfaction was noted in the relation of the participants of the current study with the other sex in comparison to the French ones in the study of Dazord (2002). One possible reason could be that the issue of relating to the other sex for patients diagnosed with schizophrenia in Greece may not receive attention as a need for the patients diagnosed with schizophrenia and is rather seen as a side effect of their medication. Therefore, the participants address it during the current study. In their study Bengtsson-Tops and Hansson (1999) found that both men and women reported that one of the areas with the highest proportion of unmet needs is counselling about intimate relationships. Sexual functioning for the patients diagnosed with schizophrenia, has received little attention or recognition as an important aspect of their quality of life and care while the extent of sexual dysfunction among people with schizophrenia remains largely unknown (Kelly and Conley 2004). Sexual dysfunction during treatment with conventional antipsychotics has been reported as a treatment side effect (Ghadirian et al. 1982; Sullivan and Lukoff 1990; MacDonald et al. 2003).

Concerning satisfaction with their spiritual life, the participants of the current study rated as important all the items under the spiritual category. The Greek patients diagnosed with schizophrenia showed similar scores of satisfaction with those of the French psychotic participants in Dazord's study, in only one factor: the world view, meaning their view about the things



happening around the world. Satisfaction with inner self, how participants feel about themselves, participation in group activities related to religion, way they see their future, and feeling free were scored lower by the Greek sample. It could be the case that the question referring to inner self was not well understood by the participants of the current study, since it was referring to reflection, reading, and daydreaming. The participants showed low satisfaction with their feeling about themselves due to their perceptions about their illness and to the stigmatisation they receive in the Greek community. However, the results of the current survey in relation to the participants' feelings of themselves are in agreement with those found in relevant studies.

Studies on the way patients diagnosed with schizophrenia see themselves are related to their self esteem. However, there has been little research on the nature and degree of self-esteem among persons with mental illness. Van Dongen (1998) explored the relation between work status and quality of life, drug attitudes, and self-esteem of 92 persons with severe mental illness. The results reported that positive self-esteem was found among all subjects and it was significantly higher in workers than in non workers. Factors such as feelings regarding functioning, valuing of work, social relationships, and activities with family were linked to participants' self-esteem. Rüsçh et al (2006) studied self esteem in sixty women with borderline personality disorders and 30 women with social phobia were recruited at three centres in Germany and Switzerland and completed stigma-related questionnaires. The authors concluded that a high level of perceived legitimacy of discrimination lead to self-stigma disorder. Self esteem in relation to schizophrenia relapses was studied by Gumley et al (2006).

Relapses refer to falling back into schizophrenia after convalescence or apparent recovery. One hundred and forty four patients diagnosed with schizophrenia completed the Personal Beliefs about Illness Questionnaire and the Rosenberg Self-Esteem Scale at entry, 3 months, 6 months, and 12 months. The findings showed that relapse was associated with the development of negative appraisals of self-blame and self-esteem. In relation to evaluations between carers and patients diagnosed with schizophrenia, Barrowclough et al (2003) found high criticism in carers and low negative self-evaluation in patients when they measured self-esteem by using a particularly detailed measure.

Another item of the findings of the current study which needs discussion refers to the last component of measuring the participants' quality of life, the expected change to the items addressed in the core questions. The overall answers indicate that the participants did expect the life domains included in the questionnaire to change to the better. The reason for the participants to be optimistic about the life domains to be better in the future could be considered in relation to the latest improvements in the mental health care in Greece due to the psychiatric reform which has taken place over in Greece the last 15 years (Karastergiou et al, 2005). This is consistent with findings in relevant studies. Björkman and Hansson (2007) investigated changes during the follow-up period of 92 patients diagnosed with schizophrenia with regard to symptoms, needs for care, psychosocial functioning, quality of life and social network. Improvements were found in a number of clinical aspects, quality of life and social network, and a decrease in use of psychiatric services during the follow-up period. The authors concluded

that changes in self-related factors such as self-esteem and self-efficacy were related to improvements in subjective quality of life as well as changes in social support and a reduction in unmet needs for care. Ritsner et al (2006) identified the factors that influence changes in satisfaction with quality of life (QOL) of patients diagnosed with schizophrenia. Data for 148 patients diagnosed with schizophrenia were collected at hospital admission and 16 months later. Findings indicate that baseline levels of symptoms, emotional distress, task oriented coping, self-esteem and friend support together explained 41% of the variability in the general QOL index 16 months later. Changes in the overall QOL of patients diagnosed with schizophrenia over time are associated with anergia - referring to their unwillingness to function- and paranoid symptoms, emotional distress, side effects, self-esteem, emotion and avoidance related coping styles, expressed emotion, and other social support. There was no significant association of age, education, and follow up duration, with general QOL.

The three last questions of the Subjective Quality of Life Profile questionnaire are illness specific and they are not included in the core questionnaire (Dazord, 2002). The participants of the current study perceived alcohol and drugs as with no importance and without expected change. On the contrary, they appeared to be less satisfied with the fact that they were under medication which at the same time was scored as important and without expectations of change. Referring to alcohol and drugs, the findings show the compliance the participants show to their doctors' advice and instructions which include cautious use of alcohol and no use of drugs. The participants of the study were all outpatients of the specific mental health

centre and had been followed up by the personnel for at least two years prior to the study. All the participants as well as all the outpatients were aware of the rules they had to follow in order to continue to belong as outpatients in the specific mental health centre. Excessive use of alcohol or use of drugs would be breach of the rules with specific consequences on their follow up. Moreover, the outpatients usually are satisfied and think of themselves as privileged to participate in the centre's activities, due to the known difficulties they would face if they were out of the centre. Therefore, they show appreciation and respect to the existing rules and laws. Concerning the low satisfaction with their medication, this is in agreement with relevant studies due to the side effects of the medication they take. The patients' diagnosed with schizophrenia attitude towards their medication is due to lack of insight into the disease, lack of recognition of the beneficial effects of the drugs, and to objective side-effects (Gerlach and Larsen, 1999). The most often reported side effects are weight gain (Kumra et al, 1996; Kane et al, 1988; Bondolfi et al, 1998), concentration problems (Buchanan et al, 1998; Conley et al, 1998), tardive dyskinesia, extrapyramidal symptoms, including acute dystonic reactions, drug-induced parkinsonism, and akathisia (Chakos et al, 1996; Morganstern and Glazer, 1993). Gerlach and Larsen (1999) examined the attitude of 53 chronic out-patients patients diagnosed with schizophrenia towards antipsychotic drugs. The negative attitude is to a high degree due to mental side-effects and a sceptical opinion about antipsychotic medication in general. In a study receiving maintenance depot antipsychotic treatment, the authors found that 60% were positive about the treatment, 32% were ambivalent and 8% had a negative attitude. Only 60% complained of side-

effects, even though 94% had objective side-effects. Mental side-effects such as subjective akathisia, dysphoria and emotional indifference were most often observed by the patients.

## **CHAPTER NINE**

### **CONCLUSIONS**

#### **8.1 Overall conclusions of the study**

The current study consisted of two phases. The methodology employed and the results of the two phases have been discussed throughout the chapters of this thesis. The purpose of this discussion section is first to evaluate the extent to which the aims of the study have been addressed and second to interpret the significance of the results to knowledge contribution.

The research question guiding this study was: what is the meaning of quality of life for the patients diagnosed with schizophrenia living in the community in Greece. The first aim of the researcher was to identify the meaning of quality of life for the patients diagnosed with schizophrenia. In order to undertake this aim the researcher used and discussed terms and views identified from the literature. The concept of quality of life remains difficult to define. Terms such as well being and life satisfaction are used interchangeably with quality of life. Several studies have examined both the objective and the subjective factors which contribute to people's quality of life. An aspect which is emphasised in the relevant literature is the research methods employed by the researchers in order to define the concept. Quantitative and qualitative as well as mixed research methods are used in order to explore aspects of quality of life. It is generally accepted that the choice of the research method depends on the researcher's aims, beliefs, and view points. The research method chosen for this study was a combination of

qualitative and quantitative methods. According to literature referring to the mental health context, the patients diagnosed with schizophrenia living in the community experience domains of quality of life similar to those experienced by patients with other illnesses. After reviewing relevant literature, the researcher defined the concept of quality of life as involving aspects of work, money, family, social relationships, psychological and spiritual well being. It is these aspects of quality of life that underpin this study.

The second aim of the research was to explore the meaning of quality of life as experienced by the patients diagnosed with schizophrenia living in the community in Greece. It is the researcher's belief that the meaning of quality of life can only be described by the subjects themselves. Therefore, semi-structured interviews were employed and eight patients diagnosed with schizophrenia, who were being followed up by a specific mental health centre, participated. The difficulty of the informants to provide a definition of quality of life was clear during the interviews. That was to be expected and as such had been considered as possibly the case when the first phase of this study was being structured. The quality of life indicators as they emerged from the interviews were categorised in five categories: work and money, family, health, social, and psychological. The findings are in agreement with the findings of other relevant studies.

The third aim was to further expand the research question and to measure the quality of life for patients diagnosed with schizophrenia living in the community in Greece by measuring it. The Subjective Quality of Life Profile (SQLP) was used for the second phase of the study, in order to measure the quality of life domains as they emerged from the interviews. The

specific tool has been validated in several illnesses as well as in healthy populations. The main criteria for selection were that the SQLP was found to include the main quality of life areas as they had been identified during the first phase and it has been translated in Greek. The quality of life domains included in the SQLP are measured in terms of satisfaction, importance, and expectation for change. Analysis of the data revealed an overall satisfaction with all the four categories of life domains, namely: functional, social, material, and spiritual, almost all the items scored as important by the participants, and they showed relatively high expectations for change in the future. The findings of this study constitute an indication of the construct validity of the Greek version of SQLP.

## **8.2 Implications of the study**

Conducting this study has been two-fold. First, as part fulfilment for a Doctorate of Philosophy and second, as knowledge contribution to the nursing and social sciences. The results produced by the study were interesting and will be helpful for health professionals in understanding the meaning of quality of life for the patients diagnosed with schizophrenia in the community. Furthermore, it will provide a substantial base of knowledge for future studies on patients diagnosed with schizophrenia not only for medical experts but also for social scientists, since the phenomenon of quality of life includes social indicators.

There was a lack of literature concerning the quality of life of the Greek patients diagnosed with schizophrenia living in the community and the current study was the first one focusing on the meaning and measuring patients'



diagnosed with schizophrenia quality of life. As identified in the literature review, the relevant existing Greek studies are related to medical science. Therefore, this study provides a valuable contribution to the current research deficit by providing a nursing contribution to what has so far been a medically dominated area in Greece. Especially for nursing science, it is expected to contribute towards a better knowledge and understanding of the meaning of quality of life for the patients suffering from schizophrenia. The quality of life domains as expressed by the participants as well as the level of importance these domains have to patients lives provides the background knowledge for mental health nurses who care for patients diagnosed with schizophrenia. The current study has been successful in providing the outpatients diagnosed with schizophrenia with a voice to comment upon their perceptions of quality of life. Qualitative data extracted the meaning of quality of life as experienced by the patients. It was the first time that they were interviewed face to face therefore, this study will encourage other nurse researchers to undertake further studies with patients diagnosed with schizophrenia with respect to quality of life.

Important aspects related to the function of the mental health community services were expressed throughout the interviews. For example, the participation in the centre's activities was identified as very important by the participants and contributed to their social functioning. The participation of more outpatients suffering from schizophrenia in occupations under supervision such as in work shops, was extracted as an important aspect for the participants of the current study. It is expected that this study will encourage initiatives related to the participation of all patients diagnosed with schizophrenia living in the community in Greece in work shops and activities

which improve their social functioning and their re-integration within the Greek community.

The extraction of the negative effects of stigmatisation on the patients' diagnosed with schizophrenia material and spiritual domains of their lives, should be evidence for actions to be taken at a national level. Furthermore, at a national level this study contributes towards policy. Taking into account that following the deinstitutionalisation programmes more patients diagnosed with schizophrenia are now living in the community (Bellali and Kalafati, 2006), this study can raise the importance of the mental health centres as well as the social benefits and allowances to both the patients and their families. In relation to the family support received by the families of the patients diagnosed with schizophrenia, this study can contribute towards policies on relevant programmes. The quantitative data from this study provides measurements of the satisfaction with life domains which contribute to quality of life as well as the importance of those domains to the patients diagnosed with schizophrenia. These results can guide actions and policies on work related issues, financial support, and public education for the patients diagnosed with schizophrenia living in the community. Moreover, the findings of this study constitute an indication of the construct validity of the Greek version of the Subjective Quality of Life Profile (SQLP).

### **8.3 Limitations of the study**

The current study has limitations. First the interviews during the first phase of the study were conducted in Greek and then translated into English. Despite the double check of the translation by the Director of the mental

health centre, there is always the risk of mis-interpretation of words and implications from one language to the other. The sample size for the interviews was adequate to collect the data needed to proceed to the second phase of the study. However, further analysis of the variables which may affect quality of life such as age, sex, education, years of sickness, in some cases lack power, making the possibility of type 2 error (Polit and Hungler, 1995). Second the Subjective Quality of Life Profile tool (Gerin et al, 1992) appeared to be the most promising tool from the literature in terms of its validity, reliability, appropriateness, and patient acceptability (Dazord, 2002). The Greek version of the SQLP was chosen from existing quality of life tools, as the most appropriate for this study, as discussed under the section detailing the selection of the quantitative tool. With hindsight a pilot study of the instruments considered for this study, would have helped in identifying the most appropriate tool for the participants of the current study and would have prevented the possibility that the SQLP reflected issues which culturally differ for French and Greek populations.

Furthermore, the comparison of the results from the current study to those from different quality of life scores which have been revealed from subjects other than Greek, also constitutes a limitation for the study. Different cultural issues as well as the differences existing in the mental health care systems and policies between the countries should also be under consideration. More specifically, cultural differences related to the family support as well as the policies referring to the employment of the patients diagnosed with schizophrenia, the social support, and the family support

should be under consideration when attempting to compare the results of this study to the results of other relevant studies.

#### **8.4 Recommendations for further research**

The current study provides as a basis for further work on the quality of life for the patients diagnosed with schizophrenia living in the community in Greece. Instead of focusing on quality of life in relation to the results of the schizophrenia treatment, studies could be done exploring ways of including the outpatients diagnosed with schizophrenia in supported employment programmes, social and community activities as well as in family education and support programmes. There is a need to explore ways on how to shift from the labels of schizophrenia to the utilisation of all abilities and capabilities of the outpatients diagnosed with schizophrenia, for the benefit of the patients themselves as well as the community and general public in Greece. Finally, Greek mental health nurses need to move from the traditional empirical research approaches in order to contribute towards nursing theory and research. More education on existing nursing theories and research methods as well as on the philosophy underpinning nursing science should be incorporated in the nursing curricula at every level of nursing education.

## **CHAPTER TEN**

### **INTERVIEWS**

#### **10.1 Interview with Alexander (A)**

**Interviewer (P)**

**P: How old are you?**

**A: Forty two**

**P: Are you married?**

**A: No**

**P: Whom do you live with?**

**A: With my mother. I have one brother, 2 years younger than me and one sister, 6 years younger than me. They also live in Athens.**

**P: What is your educational background?**

**A: I have graduated the High School**

**P: Do you work?**

**A: No, I have never worked**

**P: Could you describe your daily life for me please?**

**A: I listen to the music, read some books, watch TV, go for a walk, paint**

**P: Do you like painting?**

**A: Yes, I paint once every 20 days, I have no inspiration, that's why I paint that rarely.**

**P: What does inspire you?**

**A:** The houses with yards, village style, with flowers on the balconies. I draw with charco, I work with classic colours, I use the nair style with many colours.

**P:** Other than painting, what else do you like to do during the day?

**A:** I listen to the music a lot

**P:** What kind of music do you listen to?

**A:** Laika, rebetika (Greek music)

**P:** Do you also sing?

**A:** Yes, I like singing

**P:** What else do you like to do?

**A:** Going out with my friends (he names 4 persons which are under the same programme in the same community centre)

**P:** Other than these 4 persons, do you have other friends?

**A:** No, I do not

**P:** Do you like going out all together?

**A:** I like it very much

**P:** Why do you like it?

**A:** They are good guys, we talk

**P:** Could you tell me what gives quality to your life?

**A:** What do you mean "quality of life"?

**P:** What is it that gives quality to your life, makes your life better?

**A:** I haven't thought of such things. May I say something?

**P:** Yes

**A:** I like the girls here, in the centre

**P:** Why do you like them?

**A:** They are beautiful girls

**P:** You mean in their appearance?

**A:** Yes

**P:** What do you like to do in your life?

**A:** I like to watch TV, take a walk, I haven't thought if I would like to do other things.

**P:** What fulfils your life the most?

**A:** Music fulfils me the most

**P:** Why do you come here, to the centre?

**A:** I take my medication, pills and injections

**P:** The fact that you take medication, has an impact to your life?

**A:** No, not at all

**P:** What things cause difficulties to your life?

**A:** I can't go out with my cousins

**P:** Would you like to do so?

**A:** Yes, I would, but they go out till late and they do not accompany me

**P:** What else do you like?

**A:** To listen to songs, happy songs, with happy words. I do not want to work. My mom does the housekeeping, as well as the outdoors things, like papers to the doctors. I don't complain about anything. The guys here at the centre care about me, they take care of me

**P:** Is there anything else you would like us to talk about?

**A:** I like going to the theatre very much

**P:** Do you go often?

**A:** No

**P:** Would you like to go more often?

**A:** Yes, but I do not like the movies they show. I like Frank Sinatra, Notre Dam and so on...

**P:** Is there anything else you would like to add?

**A:** My medication helps me a lot, I feel relaxed, it helps me...

**P:** Anything else?

**A:** No, nothing else

**P:** Thank you, Alexander, for this interview.

**A:** Thank you!



## **10.2 Interview with Maria (M)**

**Interviewer (P)**

**P:** How old are you?

**M:** 36

**P:** Are you married?

**M:** No

**P:** Do you live alone?

**M:** Yes

**P:** What is your educational background?

**M:** I graduated the Elementary School

**P:** Do you work?

**M:** No

**P:** Would you like to describe your daily life for me please?

**M:** I wake up at 07.00 in the morning, I have my coffee, I go to my sisters, she lives close to me, I take her kid along with another kid of a neighbor to the school, then I go back home and do the housekeeping, I go to my sister's house and help her with the housekeeping, I bring the kids back home, I go for lunch to the public lunch offered by the church, then I go back home, I watch TV, I go out for a walk or I go to the cafeteria to see some people.

**P:** What fulfills you the most?

**M:** To be with other people. It gives me life

**P:** What do you mean?

**M:** I feel alive, I like to be with other people, to talk with them

**P:** Do you have friends?

**M:** Yes, we are 6 to 7 friends and we have coffees all together and we talk, I visit them often

**P:** What do you usually talk about?

**M:** About housekeeping, several things

**P:** What else fulfills you?

**M:** When I see my son

**P:** How old is he?

**M:** 5

**P:** Where does he live?

**M:** He is in an institute because I am sick and I cannot take care of him

**P:** What does it mean to you?

**M:** He is my first priority in my life. He fulfills my life.

**P:** How often do you visit him?

**M:** Twice a month

**P:** Would you like to see him more often?

**M:** Yes, yes, but I do not have money to buy him presents when I visit him

**P:** And what does it mean to you?

**M:** You know, it is hard to live with the social allowance only, I cannot afford to buy the things I need. Each visit to my son costs me 50 to 60 euros. The social allowance is the only income I have, and I have my expenses for my cigarettes.

**P:** You mean that you face financial difficulties?

**M:** Yes. Most of the days I go to the church and get lunch there, they offer lunch to the poor people. It makes me feel uncomfortable, but I do not have enough money to get my food every day.

**P: Why it makes you feel uncomfortable?**

**M: Because I feel shame that I cannot work to get my own money and to live**

**P: Why you cannot work?**

**M: Nobody wants to hire a sick person. They are afraid that we will make problems at work. They prefer the healthy people. In the beginning of my illness, I couldn't do anything, I couldn't work. Now I am better and I would like to work**

**P: Have you ever worked?**

**M: No. I attended some sewing courses, then I got sick. I would like to participate to the sewing programme here.**

**P: Why would you like to participate?**

**M: To be with the others, to talk with them, to spend sometime with them and to get out of my routine**

**P: Would you like to be with other people?**

**M: Yes, I miss the company of other people.**

**P: You said that you have some friends. Are they coming to this centre?**

**M: Not all of them. Two of them are living close to my place and we meet each other for a coffee during the day. Sometimes they help me out with some money. The others are coming here and I meet them when I come here too.**

**P: Would you like to have more friends?**

**M: Yes, I would like to have many friends, to go out for a walk, to exchange visits. I like to socialize but it is not easy. After they see that I am sick, they do not want my company. I do not understand why. But they prefer to be with the healthy people. Now I am ok, I take my medications and I can be with them.**

Maybe they do not want me because I am fat. I want to lose weight, it is a side effect of the medication, I will make it.

**P:** You said that you have a sister. How is your relationship with her?

**M:** I have no relationships, I just take my niece to the school sometimes. I have no help from my sister.

**P:** How do you feel about it?

**M:** Sad

**P:** Would you like to tell me what is quality of life for you?

**M:** My son, to be married, to have family, to have a normal house. In the family to be the husband who works and the wife who takes care of the kid, to have money

**P:** What would you do with the money?

**M:** I would like to buy things for my son and myself

**P:** What do you mean by "normal house?"

**M:** A big house, or an apartment. Now I live in a small room with a toilet and a small kitchen because I have no money to rent an apartment

**P:** Is there anything else that could make you satisfied?

**M:** To have a job. Not in the private sector but in the civil service

**P:** Why in the civil service?

**M:** To be sure that they will not fire me, to be secure

**P:** Is there anything else that you would like to say about the things we discussed?

**M:** Can you help me to participate to the sewing programme?

**P:** I am afraid not. I would suggest you to discuss this issue with your nurse and your doctor. They will do the best for you. Thank you for this interview

### **10.3 Interview with Michael (M)**

**Interviewer (P)**

**P: How old are you?**

**M: 56**

**P: Are you married?**

**M: Yes**

**P: Do you have children?**

**M: No**

**P: For how long have you been married?**

**M: For 10 years, but now I am getting a divorce**

**P: Do you live alone now?**

**M: Alone**

**P: Do you work?**

**M: No**

**P: What is your educational background?**

**M: I graduated the first class of Middle School**

**P: Could you please describe your daily life for me please?**

**M: Boredom**

**P: What to you mean by boredom?**

**M: Loneliness**

**P: Would you like to tell me what do you do after waking up in the morning?**

**M: Wash, I get up at 10.00, I prepare my meals, because I cook by myself, I eat, I drink a coffee, I lay down and watch TV.**

**P: Do you go out of your house?**

**M: No, just to the super market for shopping and then I return home**

**P:** Do you have any relatives close to you?

**M:** My sister visits me and she does the housekeeping for me

**P:** Do you like being in the house all day?

**M:** I like it

**P:** You said that you feel boredom and loneliness

**M:** Yes

**P:** What would you like to do in order not to feel loneliness?

**M:** I do not know, I haven't thought of it

**P:** What do you enjoy doing?

**M:** I used to own a motorbike and I was travelling a lot, now it is broken and I have no money to repair it

**P:** Did you use to work in the past?

**M:** Yes, I did

**P:** What kind of job you had?

**M:** I was working in a garage, till 1985

**P:** What happened then and you quitted?

**M:** Then I started running two shops, it didn't work out, I closed them down and then the catastrophe came...

**P:** What do you mean by "catastrophe"?

**M:** I am alone, without friends, without anything

**P:** Would you like to have friends?

**M:** Yes, I would

**P:** Why do you think you have no friends now?

**M:** Since I got crazy (he means his psychiatric disorder), they all disappeared

**P:** Can you think why they disappeared?

**M:** Due to distance

**P:** So, you would like to have friends

**M:** Yes

**P:** What else you would like to have?

**M:** I would like to have a woman to look after me, unfortunately... (he moves his head negatively)

**P:** What do you mean by "look after" you?

**M:** Housekeeping, company

**P:** If you would like to take a walk now, where would you go?

**M:** To the park

**P:** Do you like it there?

**M:** Yes

**P:** What do you like it there?

**M:** The trees, watching people jogging...

**P:** Are there any people there with whom you talk?

**M:** No

**P:** What else would you like?

**M:** My motorbike

**P:** Anything else?

**M:** Money, money is not enough

**P:** What would you do if you had money?

**M:** I would go around the world

**P:** Trips?

**M:** Yes

**P:** Why would you travel?

**M:** I like travelling

**P:** What gives quality to your life?

**M:** Nothing

**P:** Is there anything that would fulfil your life?

**M:** Love

**P:** Why are you saying this?

**M:** Because I miss it

**P:** You mean receiving love from the other people?

**M:** Yes

**P:** What would you like from the others?

**M:** To love me

**P:** How do you mean "love"?

**M:** To care about me

**P:** Is there anyone caring for you?

**M:** No

**P:** Why are you saying this?

**M:** Now, I do not have anything

**P:** Did you like the job you used to have?

**M:** Yes

**P:** Would you like to work now?

**M:** I am a diabetic, I also have Hepatitis, I can't work

**P:** What about if you could?

**M:** I would work

**P:** Why would you work?



**M:** Because I like working, I would have an occupation and money, and company, everything

**P:** If there was something to change in your life, what would it be?

**M:** A woman perhaps, I would be better, a woman to be at home to do the housekeeping

**P:** Since when are you alone?

**M:** Since 1994

**P:** Do you have other relatives?

**M:** I have two sisters and their children

**P:** Are you in conduct with them?

**M:** No

**P:** How do you perceive the fact that you do not have anyone caring for you?

**M:** With patience, I am waiting

**P:** What are you waiting for?

**M:** I hope, as all people hope

**P:** Other than a job, money, and a woman, is there anything else which you believe that would make your life better?

**M:** No

**P:** Is there anything else you would like to say concerning your quality of life?

**M:** No

**P:** Thank you for this interview

**M:** You are welcome

#### **10.4 Interview with Tasos (T)**

**Interviewer (P)**

**P:** How old are you?

**T:** 46

**P:** Are you married?

**T:** I am married and I have a son, 22 years old

**P:** Do you work?

**T:** No, I am retired

**P:** So, you had been working in the past

**T:** Yes, I was working in a company with music records, for 20 years

**P:** You were a technician?

**T:** No, as a worker

**P:** Do you live alone?

**T:** No, with my wife and my son

**P:** What is your educational background?

**T:** I graduated the Elementary School

**P:** Could you describe your daily life for me please?

**T:** I wake up at 08.00. I go to the super market, to the bakery, and then I go for a couple of hours to the cafeteria. In the afternoon, I usually go to the Goethe Institute, they have music here and they play movies

**P:** How do you have links with Goethe Institute?

**T:** I used to have a friend who was studying German there and he invited me. I had been there the other days. It is nice there; they play old German movies and non-talking movies. Sometimes I go to the football court in the afternoons, or to the cafeteria again and then I go back home

**P: What do you do at home?**

**T: I wash the dishes...and other stuff**

**P: Do you have friends?**

**T: Yes, I do**

**P: Do you have any friends in the cafeteria?**

**T: Yes, I do. On Sundays I go for mountain hiking. In the past, I used to hike long distances, to hike for 10 to 12 hours, now I go and walk for 2 to 3 hours and that's all, I do not hike when it snows either when it rains**

**P: When you say "in the past" what do you mean?**

**T: Ten years ago**

**P: Do you face any difficulties in your daily life?**

**T: My wife is a baby-sitter and I miss her a lot**

**P: Does she work long hours?**

**T: She is out of the house for 8 hours; I am alone, I listen to the music**

**P: Do you mean that you feel alone?**

**T: Yes**

**P: What does fulfill your life?**

**T: The music and the hiking. In the past, I used to record a lot, the hiking, but now it is too expensive for me; I have made many movies on hiking, children hiking, and my son when he was a kid, in the play yards...**

**P: Have you done anything with those tapes or you just watch them?**

**T: I watch them**

**P: Have you given any tapes for production?**

**T: There was a TV competition at once and I had participated, but they didn't inform me about the results, I do not know...**

**P: What satisfies you?**

**T: The music**

**P: What kind of music do you listen to?**

**T: Laika (Greek kind of music), Greek pop, I do not listen to foreign music, I do not like it**

**P: What else satisfies you?**

**T: The movies, the old movies, not the aggressive movies. I used to watch terror movies, but not any more**

**P: What are the most important things in your life?**

**T: My family, I like very much the family. If I hadn't been sick, I would have had a dozen of kids, hiking kids (he laughs)**

**P: Does your son hike?**

**T: I have taken him with me about 10 times, but he doesn't like it**

**P: You said that if you hadn't been sick, you would have had many kids**

**T: Yes**

**P: Do you mean that your illness was an obstacle for this?**

**T: I am afraid of this and my wife doesn't want**

**P: When you say "I am afraid" what do you mean?**

**T: That the kid will be sick too**

**P: You mean the kid to be born?**

**T: Yes**

**P: Is there anything specific that you afraid of and which the kid would take too?**

**T: Yes**

**P: What is it?**

**T:** I became sick because I was taking a lot of mountain hiking and due to the amount of the workload, I was working a lot, all people used to tell me: "is this your own factory and you work that much?"; and those people were talking all about politics and football, therefore I left that work

**P:** Do you talk with your friends in the cafeteria?

**T:** Yes, we talk; there is one who works in the Lyric Opera and we talk about classical music. And I know a lot about classical music, I used to have many disks and I know a lot

**P:** Do you have many friends at the cafeteria?

**T:** No, not many

**P:** With how many you are close to?

**T:** We are three all together

**P:** Are there any other things you perceive important to your life?

**T:** I can't think of anything

**P:** You told me that your wife works as a baby-sitter. Is she paid for this?

**T:** Yes, with my pension and her salary we survive

**P:** Are there things that you would like to do.... (he interrupts the interviewer)

**T:** ...and I have never done? Yes, I like the movies very much and I would like to be a director, I have a good imagination. If I show you the shots I have taken, you will think that they have been taken by a professional. I like the movies and to be a director very much

**P:** Do you think that you could do this job now?

**T:** No

**P:** Why not?

**T:** It is too late for me now. I wanted to record scenes from the mountains, to video tape a team of kids hiking the mountains and walking on the mountain, without cars, no cars at all, just walking on the mountains

**P:** If you had the chance, would you do this?

**T:** Yes, I know all the Greek mountains, when there is snow, fog...

**P:** How are your relationships with your friends?

**T:** If they do not talk seriously, I avoid them

**P:** Does this happen often?

**T:** Many times, in the cafeteria, they talk no sense and I go away

**P:** So, how many hours do you spend in the cafeteria?

**T:** Maximum two hours

**P:** In the morning when you are at home, is there anything that you would like to do?

**T:** I listen to the music

**P:** Does this fulfill you?

**T:** Yes, it does

**P:** Do you have contacts with your relatives?

**T:** Good relationships

**P:** Do you like to be with them?

**T:** Not much, we mostly contact my wife's relatives, while with mine it is not the same

**P:** You mentioned that your illness has caused you some problems in your life

**T:** I lost my job because I was under medication

**P:** Now that you are retired, has your illness caused you any problems?

**T:** Yes, I used to be active, to climb the mountains, now I cannot

**P:** In what way your illness keeps you away from what you liked to do in the past?

**T:** My thinking has changed

**P:** What do you mean?

**T:** I do not want to go for hiking, I am getting scared by the bad weather. Last time we went, we had to come back due to the heavy snow and the people in the village were laughing at us and calling us “crazy”

**P:** Other than with hiking, do you face difficulties due to your illness?

**T:** No

**P:** You are on medication, right?

**T:** Yes, I take... (he mentions all his medications). I have been registered to this centre for 17 years.

**P:** If you could change some things of your life to the better, which would be?

**T:** Not to be alone for many hours, to have my wife at home to go together to the cafeteria, to have a coffee, to smoke a cigarette, to talk together, I like this

**P:** If I would ask you what quality of life means to you, what you would say?

**T:** No drinks, no being out till late at night, to watch good movies, to listen to good music and our food to be with not much meat

**P:** What gives quality to your life?

**T:** Money makes our life good

**P:** What do you mean by this?

**T:** I want to go to the theatre and it costs 2,000 drachmas (he is not used to the euro yet) and I cannot go. I want to attend a concert at the House of Music, where they play very nice concerts and I cannot go. The other days

there was a movie with orchestra music, the ticket was 2,000 drachmas and I couldn't go

**P:** Is there anything else concerning your quality of life?

**T:** I am fine, I am calm

**P:** Would you like anything to change?

**T:** To work in a TV channel

**P:** You mean to have a job?

**T:** Yes

**P:** Anything else?

**T:** No

**P:** Is there anything else you would like to add to our conversation?

**T:** No

**P:** Thank you for this interview

**T:** You are welcome



### **10.5 Interview with Anna – Maria (AM)**

**Interviewer (P)**

**P: How old are you?**

**AM: 34**

**P: Are you married?**

**AM: No**

**P: Do you live alone?**

**AM: With my parents**

**P: Do you work?**

**AM: I haven't been working for 12 years now**

**P: What is your educational background?**

**AM: I graduated the High school, I sat for the exams to enter the University, the Law School, but I failed because I was not very good in my classes. I was a good student but not an excellent one in order to enter the Law school in the University. The exams are hard, I didn't manage it. Then I took sew classes. I have the specialization in sewing, but I cannot work because I am not productive due to my health problem, it doesn't help me to work outside, they want high productivity**

**P: What do you mean: "I am not productive"?**

**AM: They want me to produce 50 pieces every day, I mean 50 formats every day, I know how to draw a format. I couldn't produce 50 formats every day, it is very hard. Because of my health is a bit... (stops for a while) and with the medication, it is not permitted to be fast. They want me to be fast and I am not. Prior to my sickness, I was different, much different. In the past I was flying, I was not excellent though. I was a normal person, a productive person,**

like a healthy person. Not even this I can be now that I am sick, not even normal

**P:** In what way you are different from normal, now that you are sick?

**AM:** Now I am slow, I cannot do my work fast

**P:** You mean to move fast?

**AM:** Yes, to move fast. Yes, that's it. For example: out of the first format, I want to produce 50 patrons. I have to measure it, to give an idea, something mine, something new and I cannot. My hand reaches the 20<sup>th</sup> and I am exhausted

**P:** You mean that you get tired with the quantity

**AM:** It gets me tired and I cannot go on

**P:** Would you like to describe your daily life for me please?

**AM:** I wake up at 07.30 in the morning, I take my milk, I wash my face, brush my teeth, get dressed, if I can I put some lipstick on, my earrings, just to be a bit beautiful and I have to be at the bus stop at 08.00, the bus comes at 08.10. I must be at the bus stop that time, because if I miss the bus, the next one comes after half hour, because public transportation is not very good. I arrive here at 09.30. I sit there with the other guys, we talk together until we start, I love them and they love me, and then we start to do what Mrs Kika says; we make the dry flowers for the shop (she means the Lotos Shop), we take breaks, we have a nice time, we structure, it is not that easy but day by day and with the experience I manage it and then the second break is a bit longer than the first one. I finish at 13.00. I take the bus and I am back home at 14.30 or 15.00. I arrive home, I cannot do anything else, I wash my hands, change clothes, and then immediately I have lunch. My father prepares and serves it,

**I take my time while eating, sometimes when my father is tired I serve the meal, till 16.30 I eat. Then I watch TV till 17.00 and I take a nap till 18.00, then I get up, I knit, I study English a bit, I have a book, I go for shopping or I do some house work, I clean up the rooms, the toilet. It means that till 21.00 I do the housekeeping. I do not do the heavy house work, (she explains) to wash the walls is a heavy work for me, but I do all the rest; wash the dishes, the balcony. My father does not let me sleep long, either to sit around without doing any housekeeping**

**P: And after 21.00?**

**AM: I have my dinner at 21.00, I may have taken a shower, I am clean, I dine, I watch TV till 23.00. Then I go in bed because I wake up early to come over here**

**P: What do you like most, what fulfills you most; out of all the things you do every day?**

**AM: It fulfills me being at home and when I am here**

**P: Why do you like these?**

**AM: Because I keep myself busy and it is a very interesting work and occupation, it looks like a day hospital. It seems to me like an institute because we are with doctors and nurses all the time**

**P: What does it mean to you?**

**AM: I like it because I feel that I am not alone, that I belong to somewhere, that I have some ones who could help me , so when I come here I do not feel alone, there are persons here who can help me when I need them. It is an occupation and an institute at the same time. It fulfills me; my home also fulfills me in the evenings**

**P:** You say that you like it because it is an occupation

**AM:** Yes, it is a very nice occupation because outside it is not easy to find a place to create and to be productive. Here it is not necessary to be productive

**P:** Out of what you said so far, the most important to you is your occupation here?

**AM:** Yes, here and at home

**P:** You said that you like it here because you create things without having to be productive. What else do you like in this centre?

**AM:** I like the guys I see, the friends I have, we are all sick and this is common for all of us, I have company because I cannot have friends

**P:** Why you cannot have friends?

**AM:** Because I am not in their society very much, I am a bit out of their society. Most people have their jobs and socialize, they talk about common interests, I cannot say anything interesting about my job, only about my activities in the centre; they have something new to discuss every day, and they earn good money, while I take the social allowance which is not enough either for me or to contribute financially at home. They take a lot more and they can do what they want, while I cannot

**P:** What would you like to do and you cannot because the money is not enough?

**AM:** It doesn't bother me because I am used to this kind of life, I am used

**P:** You talked about the others who are not sick while you are

**AM:** Yes

**P:** Do you think that... (she interrupts the interviewer)

**AM:** They see that there is something wrong going on with me and then they avoid me and me as their company. I have met quite a few people who do not want me as their company

**P:** Have you ever thought of what makes them not to want you as their company?

**AM:** I do not know, after sometime they understand that I have a problem, because I cannot talk with them about my interests, their interests, and those girls find a healthy boyfriend. I have met a boyfriend lately, he loves me much, he is like a present for me, now I have a friend. Since 10 years, he has been without medication, he is ok, he had a serious problem, now he doesn't take medications any more. He works at his father's garage, he repairs cars. He is the person that when you see him, you say that he was not sick, he was not on medication. He is a healthy man but he loves me. He understands me because he was on medication in the past and he understands me

**P:** Do you like it when you two are together?

**AM:** Very much

**P:** How do you feel when you two are together?

**AM:** I feel happy, happy with him, we go out

**P:** Do you two go out often?

**AM:** No, only during the weekends we go out. He works all day and he is tired, we cannot go out

**P:** Do you enjoy it?

**AM:** I do. Dimitris (his name) was surprised that I am faithful to him. He told me: "if you are faithful to me, you will get everything from me, if you are not

demanding, if you do not ask for presents all the time, if you are not arrogant...”

**P:** Does this relationship fulfill you?

**AM:** Much

**P:** If it was to change something in your life, what would it be?

**AM:** First of all my health. To be healthy, not sick

**P:** If you had changed it and you were healthy, what would you do?

**AM:** I would find a job o work, I would earn money

**P:** What would you do with that money?

**AM:** I would deposit it to buy a house for me, to buy clothes which make me beautiful and to go out and have fun, to keep some for the future

**P:** To have fun, can you have fun now?

**AM:** No, I cannot go out and have fun now

**P:** What do you mean by “fun”?

**AM:** To attend a concert, to go out for a drink which I cannot do now due to the side effects of my medication, they exhaust me. Even if I were healthy, I wouldn't go out for fun every night, I would go once a month. I had been out till late once, and the music started at 00.00, I left at 01.00 because my head was so dizzy, I was hearing voices, other than those voices they say (she moves her hand close to her mind, meaning the crazy people). I couldn't understand the songs because I had a psychological problem

**P:** Was it tiring?

**AM:** Yes, it was

**P:** How are your relationships with your relatives?

**AM:** Very good. Six years ago I was in the guest apartments because I had made my father feel tired, now I am ok and we have been together for the last 6 years. Lately he told me that he would take me to the guest apartment again, but he didn't say it in a bad way. He told me to stay there, till I get the social allowance. If I start getting the social allowance, we will have money

**P:** What does quality of life mean to you?

**AM:** My only quality in my life is when I come here to the centre, that I live in a house with my father, that I have Dimitris. This is all quality of life for me, I do not know what it is for someone else, for me it is everything, it is a very good quality.

**P:** You mean that the fact that you are coming here, that you live with your father, and that you have Dimitri . These give quality to your life

**AM:** Yes, indeed, they give much quality

**P:** Is there anything else you would like to say on what we have discussed?

**AM:** No, nothing else

**P:** Thank you for this interview

**AM:** Thank you for listening to me

## **10.6 Interview with Martha (M)**

**Interviewer (P)**

**P:** How old are you?

**M:** 31, I have been sick since my 22, but I have been coming to the centre here for 4 years

**P:** Are you married?

**M:** No

**P:** Do you have a job?

**M:** I take only the social allowance which is very few money, so I started working once a week and then twice a week and finally every day in a courier company. I had to walk 3 to 4 hours every day and my salary was 16 euros every day. It was not legal, because I was not supposed to have a job while being under the social allowance system. Therefore, I had to lie that I do not work and to take the social allowance, so the system makes you a liar. Now I come to the centre and I work part-time.

**P:** Do you live alone?

**M:** I live with my mom, at her house. It is a 45 square meters, I mean we live as we used to live when I was a kid, we have done nothing to change it

**P:** What is your educational background?

**M:** I graduated the High School and I wanted to go on and to study abroad, but I didn't go

**P:** I would like you to describe your daily life for me please

**M:** Do you mean now or while I was working?

**P:** I would like you to describe your daily life as it is now, please.



**M:** I wake up at 07.00 or 07.30, I listen to the radio, I take a shower, I read, I go for a walk for one or two hours because I am worried of gaining weight, I go back home, do some housekeeping, I paint (lately I do not paint much), in the evening after my walk I read, listen to the radio, cook ... and stuff like that. Sometimes I put in order some newspapers or I study English. You know? For three years, out of the 10 years I am sick, I was experience a negative attitude, I think it was unfair for myself, if not a sin... I was very sad and then my illness showed up and I said I do not want to do, to think anything; I am a "nothing". That lasted for 3 years ...

(Martha goes on and talks very fast and she goes from one issue to another.  
The interviewer brings her back to the topic)

**P:** So, your interests include reading, walking, listening to the radio and painting

**M:** Learning foreign languages too, English, French and now I want to learn the deaf-mute language; I applied to the Deaf-mute Institute.

**P:** You are an active person

**M:** If you ask the people here, they will tell you that this girl is another person, it is not the appearance, it is the eye sight. You know, when we are sick, I had seen this in the mirror, we focus on one point to freeze the time. You are into your problem. Now you can see that I communicate, I may be ugly, I am not the beauty model, but you see, I shine.

**P:** Out of all these you told me, what fulfills you?

**M:** It fulfills me to meet people, when I go to get a coffee, because only when you have money you will give 3 euros for a coffee

**P:** You are talking about money, do you think it is a problem?

**M:** It is the way out, if you have privileges, you do not need money

**P:** What do you mean?

**M:** For example: you want to go out, you need to wear the appropriate clothes and to enter, it is like a ghetto. The logical people have much and they want to have more... Being logical means to want more. How then we can compare the worst with the best? What fulfills me? It fulfills me, I am not saying it egoistically because I have psychiatric problems, I want to make people laugh. If I could start my life, I would like to be a psychologist, but I do not know if I would be good because I am not writing right, I haven't studied Chemistry. I think that I can understand people, I would do this as a hobby and not for money

(the interviewer brings her again back to the topic)

**P:** What does fulfill you most?

**M:** My relationships with my girlfriends and with the other sex. Now I do not have a boyfriend, my last one was 3 years and 3 months ago.

**P:** Did it fulfill you?

**M:** Very much, I could see how men think; I do not have any brother, I am the only child and it was important to me. Reading fulfills me much

**P:** What about your relationships with your girlfriends?

**M:** The one knows that I am sick because we were working together. With the other one, we became friends through our moms' relationship. She doesn't know that I am sick, she wants to be a psychologist and I think that she understands that I am sick; I do not know when I will find the right moment to tell her that I am sick because it makes me feel uncomfortable; you know then

questions start like: what are you doing there? where do you work? and so on...

**P:** Do you think that your illness holds you back from socializing?

**M:** No, it is the others who take it wrong. For example: last summer there was an exhibition held by Dromokaetio (mental health hospital in Athens) and one lady asked me: "where did you know about this exhibition from?" and she laughed at me trying to hide her smile and I pretended that I didn't understand it. When you tell them that you have a problem, it is like a glass frame stands in between you and them, the handicapped may have a body part missing, with us it is something that is not visible (she means the sickness).

**P:** Does this happen often?

**M:** The second time was at work. In the beginning, my boss didn't know that I am sick, but then she knew it. People change when they know that you are mentally sick...

**P:** Do you think that her behavior changed after she knew about your illness?

**M:** Yes, because afterwards she treated me like her slave

**P:** Have you experienced the same behavior from others too?

**M:** Yes, in the Social Allowances office.

**P:** What does quality of life mean to you?

**M:** To respect the others, to respect the minorities and the different people

**P:** Anything else?

**M:** No, nothing else

**P:** Would you like to say anything more?

**M:** No

**P:** Thank you for this interview

**M:** It was nice; I liked it (she smiles)

### **10.7 Interview with Soula**

**Interviewer (P)**

**P:** How old are you?

**S:** 35

**P:** Are you married?

**S:** No

**P:** Do you live alone?

**S:** I live in the centre's apartment with a roommate

**P:** For how long have you been living there?

**S:** For two years

**P:** What is your educational background?

**S:** I graduated the Middle School in Germany

**P:** Do you work?

**S:** I participate into the sewing programme of the centre

**P:** Could you describe your daily life for me please/

**S:** From 09.00 till 13.00 I go to the sewing department, then I go back home, I eat we cook alternatively with my roommate, and then I visit friends. Not every day...

**P:** From these you do every day, what you like doing the most?

**S:** Taking walks

**P:** Do you take walks often?

**S: Yes**

**P: When do you usually take a walk?**

**S: In the late afternoons**

**P: Where do you go?**

**S: I visit one girlfriend of my, she lives in the guests' apartments. I used to live there in the past. And I also visit a friend, he lives in a centre's apartment too.**

**P: You said that you like visiting friends. Do you have many friends?**

**S: The girlfriend living in the guests' apartments, the boyfriend living in the centre's apartment and one more boyfriend living in his own house.**

**P: All of them are members of the community mental health centre?**

**S: Only the two of them**

**P: Do you like being all together?**

**S: Yes, we have a nice time, they are my friends and I love them**

**P: How do you all spend your time together?**

**S: We talk**

**P: Do you like talking with them?**

**S: Yes**

**P: Out of those things you daily do, are there any which are difficult for you?**

**S: No, everything is ok**

**P: Is there anything you would like to do in your life?**

**S: I would like to get a job**

**P: Why would you like to get a job?**

**S: To keep me busy and to improve my financial status. The social allowance is not enough**

**P: You said that the social allowance is not enough. Enough to do what?**

**S:** To buy cigarettes, clothes...

**P:** To clarify: if you had a job and earned more money, what you would do?

**S:** I would like to learn foreign languages, but I see it difficult because they ask for money there

**P:** Do you mean that if you had money, you would go and study?

**S:** I would

**P:** What else would you do?

**S:** Nothing special

**P:** Do you think that these would ... (she interrupts the interviewer)

**S:** ...would fulfill me

**P:** What does quality of life mean to you?

**S:** No (she moves her head negatively)

**P:** Those you mentioned before, about money, job, studies which would fulfill your life, would they also make it better?

**S:** I would certainly feel better

**P:** What do you mean?

**S:** More full, more satisfied

**P:** You would feel more fulfilled and satisfied?

**S:** Yes

**P:** What do you think of living in the centre's apartment?

**S:** I am very lucky

**P:** Why are you saying so?

**S:** Because it is great luck to live in those apartments

**P:** Why?

**S:** It is very convenient, the social allowance is not enough to pay the rent for an apartment

**P:** Couldn't you afford to pay the rent for an apartment?

**S:** No

**P:** How is it living in that apartment?

**S:** Good

**P:** What are the difficulties you face there?

**S:** Nothing is difficult

**P:** You said that you and your roommate cook alternatively

**S:** I do not know, it has to be done, I am not fun of cooking, but I cook

**P:** Are you on medication?

**S:** Yes

**P:** Do you have any problems... (she interrupts)

**S:** No, now I am used to it, in the beginning it was difficult to admit that I am sick, then I got used, now it doesn't bother me

**P:** You said that it was difficult to admit, what do you mean?

**S:** I hadn't realized it

**P:** And how did you feel about it?

**S:** It was just a realization

**P:** How do you feel about it now?

**S:** Nothing, it is ok, all is fine

**P:** Do you keep contact with your family?

**S:** Just the necessary things

**P:** What do you mean by "only the necessary"?

**S:** You know, some phone calls and short visits

**P:** Is there anything else, other than the job and the financial issues, you would like to mention?

**S:** I would like to learn how to use a computer

**P:** Do you like it?

**S:** I think it is necessary today

**P:** Necessary, for what?

**S:** Wherever you go, they ask you if you know to use them. I used to take classes but I quitted

**P:** Why did you quit?

**S:** Because I moved to another house and it was far away

**P:** Did you like it?

**S:** Yes

**P:** Would you like to star it again?

**S:** Yes, yes

**P:** What do you do during your free time?

**S:** I listen to the music

**P:** Do you like it?

**S:** Yes

**P:** Anything else?

**S:** I like The little dolls

**P:** Why?

**S:** I do not know, I like them

**P:** Is there anything else you would like to say about all we discussed today?

**S:** No

**P:** Thank you for this interview



**S: You are welcome**

### **10.8 Interview with Vasiliki (V)**

**Interviewer (P)**

**P: How old are you?**

**V: 50**

**P: Are you married?**

**V: Yes**

**P: Do you have children?**

**V: Yes, two**

**P: How old are they?**

**V: 32 and 30**

**P: Do you live all together?**

**V: I live with my husband and our oldest daughter who is not married**

**P: Do you have a job?**

**V: No, I go to the Lotos Shop**

**P: What is your educational background?**

**V: I have graduated the Elementary School. I am from Imvros and I didn't go on to higher education**

**P: Could you describe your daily life for me please?**

**V: I get up in the morning, I go to the shop (she means the Lotos Shop), then I go back home, I cook, I do some working in the house, if there is something, I watch TV, I knit.**

**P: How many hours do you spend in the shop?**

**V:** From 09.00 till 13.00

**P:** And what do you usually do in the afternoon?

**V:** I usually do nothing. After I finish the in house work, I knit, I watch TV, I do not go out even though I must in order to loose weight

**P:** Would you like to loose weight?

**V:** Yes, yes. I have always been fatty

**P:** Out of those you described to me, what do you like to do most? What fulfills you?

**V:** All of those fulfil me, whatever I do... I haven't thought of my life without Lotos because I do not know what I would do, the whole day at home... I do not know what I would do. (she raises her shoulders like questioning herself)

**P:** Does working fulfil you?

**V:** Yes

**P:** Why?

**V:** We have a company with the girls, we talk, we work, we take our time together, then I go home

**P:** You mean that the most important of the daily things you do, is your work at Lotos?

**V:** Yes, yes

**P:** Is there anything else you would like to do but you can't for some reasons?

**V:** I would like to work outside (she means out of Lotos), but I do not manage it. Whenever I got a job out, I had relapses. Working for nine hours is too much. We, who take medications, are getting tired

**P:** Do you mean physically tired?

**V:** Physically and then it comes

**P:** What do you mean "it comes"?

**V:** The relapse

**P:** For how long you have been under medication?

**V:** Since '74, approximately

**P:** If I would ask you what quality of life means to you, could you tell me what gives quality to your life?

**V:** Difficult question

**P:** Is there anything which could make your life better?

**V:** No, I am happy, I would just like not to take medications

**P:** Why would you like not to take medications?

**V:** To work like all the other people, to contribute to the family

**P:** What do you mean by "contribute"?

**V:** And money and... I would help the family, it is just my husband... we do not make it...we just survive

**P:** If you had more money, what would change?

**V:** It would be better

**P:** What do you mean?

**V:** More than I can do now; it is just for the super market shopping, the house rent and common charges, electricity, phone bills

**P:** You mean that if you had more money, you would have all those expenses to pay and what else you would do?

**V:** Yes, and I would have some more to spend for myself and my family

**P:** Have you thought what you could do if you had money?

**V:** To buy some clothes for me and to help my children, to buy a present for them, because I buy presents only for holidays and even that is difficult

**P:** Do you like to give presents?

**V:** Yes

**P:** How do you spend your free time?

**V:** I knit and my husband complains that I do nothing else, we do not chat, we do nothing else and he says: "you are with the knit needle all the time"

**P:** Do you knit for the family?

**V:** Yes, they like them; for the family and for our relatives

**P:** Do you have relatives?

**V:** Yes

**P:** Do you keep in touch?

**V:** Yes, yes we visit them often and they visit us

**P:** How do you like it?

**V:** Yes, yes

**P:** Do you socialize with others?

**V:** Yes, Eve, I have been to her place. I do not socialize with the others from the community centre. I do not have friends, I socialize with our relatives, we have coffees at my mother's in law house

**P:** How do you like this?

**V:** Yes, I like it

**P:** Out of what you have said so far, what is the most important thing you like to do, other than going to the Lotos Shop?

**V:** My family, to contribute to my family, to cook for them, to knit, to iron, to take care of them

**P:** Do these satisfy you?

**V:** Yes, yes

**P: After saying these, would you say that you your life has quality?**

**V: Yes, I would say that it has quality, my life is full, I do not have time to just sit around**

**P: Is there anything you do not like and you would like to change?**

**V: I like everything, there is nothing I do not like**

**P: You said that you would like to work out, why you think that you cannot work out?**

**V: All the times I had a job, I had a job in a Taverna (traditional Greek restaurant) and in a dry cleaners shop. In the dry cleaners I didn't relapse, the owner changed, my brother in law took the shop and I left. I had been 3 times in the Taverna of my other brother in law, but I cannot stand the night shift. To finish at 03.00 in the morning, to go in bed at 04.00, to do the housekeeping in the morning and the evening to go again to the Taverna...**

**P: It was tiring?**

**V: Yes, I had also worked evening shift, but again, 9 hours is exhausting, a lot of work, dish washing, cooking**

**P: For how long had you been working there?**

**V: Evening shift for a summer season and 3 night shifts**

**P: Would you like to work there again?**

**V: No, it is exhausting**

**P: Is there anything else you would like to tell me about the quality of your life??**

**V: No**

**P: Thank you for this interview**

**V: You are welcome**

## REFERENCES

- Aamodt, A.M. (1989). Ethnography and epistemology: generating nursing knowledge. In: Morse, J. M. (ed). Qualitative Nursing Research: a contemporary dialogue (pp. 40-53). Sage Publications, Newbury Park, USA.
- Aaronson, N.K. (1990). Quality of life research in cancer clinical trials: A need for common rules and language, Oncology, 4(5), pp. 59-66.
- Aaronson, N.K.; Acquadro, C.; Alonso, J.; Apolone, G.; Bucquet, D.; Bullinger, M.; Bungay, K.; Fukuhara, S.; Gandek, B.; Keller, S. (1992). International Quality of Life Assessment (IQOLA) Project, Quality of Life Research, 1, pp. 349-51.
- Aleman, A.; Kahn, R. S.; and Selten J.P. (2003). Sex Differences in the Risk of Schizophrenia, Archives of General Psychiatry, 60, pp. 565-571.
- Allison, D. B.; Mackell, J. A.; and McDonnell, D. D. (2003). The Impact of Weight Gain on Quality of Life Among Persons With Schizophrenia, Psychiatric Services, 54, pp. 565-567.
- Alverson, H.; Alverson, M.; Drake, R. E. (2000). An Ethnographic Study of the Longitudinal Course of Substance Abuse Among People with Severe Mental Illness, Community Mental Health Journal, 36 (6), pp. 557-569
- Anderson, R.L. and Lewis, D.A. (2000). Quality of life of persons with severe mental illness living in an intermediate care facility, Journal of Clinical Psychology, 56 (4), pp. 575-581.

- Anderson, R.M.; Sullivan, F.; and Usherwood, T.P. (1990). The Medical Outcomes Study Instrument (MOSI) – use of a new health study instrument in Britain, Family Practitioner, 7, pp. 205-218.
- Andrew, G.; Peters, L.; and Teeson, M. (1994). Measurement of Consumer Outcome in Mental Health, NSW, Australia: University of New South Wales, Clinical Research Unit for Anxiety Disorders.
- Andrews, F.M. (1974). Social indicators of perceived quality of life, Social Indicators Research, 1, pp. 279-299.
- Andrews, F.M. and Withey, S.B. (1976). Social Indicators of Well-Being: Americans' Perceptions of Life Quality, Plenum Press, New York, USA.
- Angell, B. and Test, M. (2002). The relationship of clinical factors and environmental opportunities to social functioning in young adults with schizophrenia, Schizophrenia Bulletin, 28 (2), pp. 259–271.
- Angermeyer, M. C. and Schulze, B. (2001). Reinforcing stereotypes: How the focus on forensic cases in news reporting may influence public attitudes towards the mentally ill, International Journal of Law and Psychiatry, 24, pp. 469–486.
- Angermeyer, M.C. and Matschinger, H. (2003). The stigma of mental illness: effects on labelling on public attitudes towards people with mental disorder, Acta Psychiatrica Scandinavica, 108, pp. 304-309.

- Aristotle. (1941). In McKeon (ed). The basic work of Aristotle, New York: Random House.
- Awad, A.G.; Voruganti, L.; and Heslegrave, R. (1997). A conceptual model of quality of life in schizophrenia: description and preliminary clinical validation, Quality of Life Research, 6, pp. 21–26.
- Bacani-Oropilla, T.; Lippmann, S.; Tully, E.; and Jaegggers, K. (1991). Patients with mental disorders who work, Southern Medical Journal, 84, pp. 323 -327.
- Barbato, A. and D'Avanzo, B. (2000). Family interventions in schizophrenia and related disorders: a critical review of clinical trials, Acta Psychiatrica Scandinavica, 102 (2), pp. 81-97.
- Barr, W. (2000). Characteristics of severely mentally ill patients on and out of contact with community mental health services, Journal of Advanced Nursing, 31 (5), pp. 1189-1198.
- Barrowclough, C.; Tarrier, N.; Humphreys, L.; Ward, J.; Gregg, L.; and Andrews, B. (2003). Self-esteem in schizophrenia: relationships between self-evaluation, family attitudes, and symptomatology, Journal of Abnormal Psychology, 112, pp. 92–99.
- Basch, C.E. (1987). Focus group interview: An underutilized research technique for improving theory and practice in health education, Health Education Quarterly, 14, pp. 411- 448.



- Becker, D. R.; Bond, G. R.; McCarthy, D.; Thompson, D.; Xie, H.; McHugo, G. J.; Drake, R. E. (2001). Converting Day Treatment Centres to Supported Employment Programs in Rhode Island, *Psychiatric Services*, Vol. 52 (3), pp. 351-357.
- Beer, R.M. (2002). The British reaction to dementia praecox 1893-1913. Part 1, *History of Psychiatry*, 13 (51), pp. 285-304.
- Bellack, A.S.; Mueser, K.T.; Morrison, R.L.; Tierney A.; and Podell, K. (1990). Remediation of cognitive deficits in schizophrenia, *American Journal of Psychiatry*, 147, pp. 1650-1655.
- Bellali, T. and Kalafati, M. (2006). Greek psychiatric care reform: new perspectives and challenges for community mental health nursing, *Journal of Psychiatric Mental Health Nursing*, 13 (1), pp. 33-39.
- Bengtsson-Tops, A. and Hansson, L. (1999). Clinical and social needs of schizophrenic outpatients living in the community: The relationship between needs and subjective quality of life, *Social Psychiatry and Psychiatric Epidemiology*, 34 (10), pp. 513-518.
- Bengtsson-Tops, A. and Hansson, L. (2001). Quantitative and qualitative aspects of the social network in schizophrenic patients living in the community. Relationship to sociodemographic characteristics and clinical factors and subjective quality of life, *International Journal of Social Psychiatry*, 47 (3), pp. 67-77.

- Benner, P. (1985). Quality of life: a phenomenological perspective on explanation, prediction, and understanding in nursing science, Advances in Nursing Science, 8 (1), pp. 1-14.
- Benton, D.C. (1991). In Cormack, D. (ed), The Research Process in Nursing, (pp. 129-138), 2<sup>nd</sup> edition, Blackwell Scientific Publications, London, UK.
- Berribal. K.L. and While, A. (1994). Collecting data using a semi-structured interview: a discussion paper, Journal of Advanced Nursing, 19, pp. 328-335.
- Beusterian, K.M.; Steinwald, B; and Ware, J.E. (1996). Usefulness of the SF-36 Health Survey in measuring health outcomes in the depressed elderly, Journal of Geriatric Psychiatry Neurology, 9 (1), pp. 13-21.
- Bigelow, D. A.; Gareua, M. J. and Young, D. J. (1990). A quality of life interview, Psychosocial Rehabilitation Journal, 14, pp. 94-98.
- Björkman, T. and Hansson, L. (2007). Case Management for Individuals with a Severe Mental Illness: A 6-Year Follow-Up Study, International Journal of Social Psychiatry, 53, pp. 12 - 22.
- Bobes, J.; Gutierrez, M.; Gibert, J.; Gonzalez, M. P.; Herraiz, L.; and Fernandez, A. (1998). Quality of life in schizophrenia: Long term follow up in 362 chronic Spanish schizophrenic outpatients

- undergoing risperidone maintenance treatments, European Psychiatry, 13, pp. 158–163.
- Bondolfi, G.; Dufour, H.; Patris, M.; May, J.P.; Billeter, U.; Eap, C.B.; Baumann, P. (Risperidone Study Group) (1998). Risperidone versus clozapine in treatment-resistant chronic schizophrenia: a randomized double-blind study, American Journal of Psychiatry, 155, pp. 499–504.
- Bousquet, J.; Knani, J.; Dhivert, H. Et al. (1994). Quality of life in asthma. 1. Internal consistency and validity of the SF-36 questionnaire, American Journal of Respiratory Critical Care Medicine, 149 (2), pp.371-375.
- Brazier, J.E.; Harper, R.; Jones, N.M. ; O'Cathain, A.; Thomas, K.J.; Usherwood, T.; Westlake, L. (1992). Validating the SF-36 health survey questionnaire: new outcome measure for primary care, British Medical Journal, 305, pp. 160-164.
- Brown, C. (1996). A comparison of living situation and loneliness for people with mental illness, Psychosocial Rehabilitation Journal, 20, pp. 59–63.
- Browne, S.; Roe, M.; Lane, A.; Gervin, M.; Morris, M.; Kinsella, A.; Larkin C.; and O'Callaghan, E. (1996). Quality of life in schizophrenia: relationship to sociodemographic factors, symptomatology and tardive dyskinesia. Acta Psychiatrica Scandinavica, 94, pp. 118–124.

- Buchanan, R.W.; Breier, A.; Kirkpatrick, B.; Ball, P.; Carpenter, W.T.Jr. (1998). Positive and negative system response to clozapine in schizophrenic patients with and without the deficit syndrome, American Journal of Psychiatry, 155, pp. 751-760.
- Burkhardt, M. and Nagai-Jacobson, M. (1985). Dealing with spiritual concerns of clients in the community, Journal of Community Health Nursing, 2, pp. 191–198.
- Burnard, P. (1991). A method of analysing interview transcripts in qualitative research, Nurse Educator Today, 11, pp. 461-466.
- Burns, N. and Grove, S.K. (1999). Understanding Nursing Research, (2<sup>nd</sup> edn). Philadelphia: W.B. Saunders Company.
- Carpenter, W.T. and Buchanan, R.W. (1995). Schizophrenia: introduction and overview. In: H.I. Kaplan and B.J. Sadock, Editors, Comprehensive Textbook of Psychiatry, VI, Williams and Wilkins, Baltimore, pp. 890–895.
- Carpiniello, B.; Lai, G.; Pariente, C.M.; Carta, M.G.; and Rudas, N. (1997). Symptoms, standards of living and subjective quality of life: a comparative study of schizophrenic and depressed out-patients, Acta Psychiatrica Scandinavica, 96, pp. 235–241
- Carr, L. T. (1994) The strengths and weaknesses of quantitative and qualitative research: what method for nursing? Journal of Advanced Nursing, 20, pp. 716-721.

Cella, D. (1992). Quality of life: the concept, Journal of Palliative Care, 8 (3), pp. 8-13.

Chahraoui,K.; Danino, A.; Bénony,H.; Frachebois,C.; Clerc, A.C.; Malka, G. (2006). Anxiety and subjective quality of life preoperatively and 4 months after reduction mammoplasty, Journal of Psychosomatic Research, 61 (6), pp. 801-806.

Chakos, M.; Alvir, J.M.; Bilder, R.; Mayerhoff, D.; Woerner, M.G.; Borenstein, M; Geisler, S.; Kane, J.M.; and Lieberman, J.A. (1996). Incidence and correlates of tardive dyskinesia in first episode of schizophrenia, Archives of General Psychiatry, 53, pp. 313–319.

Chan, S. and Yu, I.W. (2004). Quality of life of clients with schizophrenia, Journal of Advanced Nursing, 45 (1), pp. 72-83.

Chinn, P.L. and Jacobs, M.K. (1987). Theory and Nursing, a systematic approach, 2<sup>nd</sup> edition, pp 33-62. The CV Mosby Company, Missouri, USA.

Chiovitti, R.F. and Piran, N. (2003). Rigour and grounded theory research, Journal of Advanced Nursing, 44 (4), pp. 427–435.

Chisholm, D.; Healey A.; and Knapp M. (1997). QALYs and mental health care, Social Psychiatry and Psychiatric Epidemiology, 32 (2), pp. 68-75.

- Cody, W.K. (2000). Nursing Science Frameworks for Practice and Research as Means of Knowing Self, Nursing Science Quarterly, 13 (3), pp. 188-195.
- Coffey, M. (1998). Schizophrenia: a review of current research and thinking, Journal of Clinical Nursing, 7 (6), pp. 489-492.
- Collins, E.J.; Hogan T.P.; and Desai, H. (1991). Measurement of therapeutic response in schizophrenia. A critical survey, Schizophrenia Research, 5, pp. 249-253.
- Conley, R.R.; Tamminga, C.A.; Bartko, J.J.; Richardson, C.; Peszke, M.; Lingle, J.; Hegerty, J.; Love, R.; Gounaris, C.; Zaremba, S. (1998). Olanzapine compared with chlorpromazine in treatment-resistant schizophrenia, American Journal of Psychiatry, 155, pp. 914-920.
- Cook, J. A. and Razzanno, L. (2000). Vocational rehabilitation for persons with schizophrenia: recent research and implications for practice, Schizophrenia Bulletin, 26, pp. 204 -208.
- Cormack, D. (2000). The Research Process in Nursing, 4<sup>th</sup> edition. Blackwell Science Ltd, UK.
- Corrigan, P. and Buican, B. (1995). The needs and resources assessment interview for severely mentally ill adults, Psychiatric Services, 46, pp. 504-5.

- Corrigan, P. and Penn, D. (1999). Lessons from social psychology on discrediting psychiatric stigma, *American Psychologist*, 54, pp. 765-776.
- Corrigan, P.W. and Buican, B. (1995). The construct validity of subjective quality of life for the severely mentally ill, *Journal of Nervous and Mental Disease*, 183, pp. 281–285.
- Crane-Ross, D.; Roth, D.; Lauber, B.G. (2000). Consumers' and case managers' perceptions of mental health and community support service needs, *Community Mental Health Journal* ,36, pp. 161-178.
- Crisp, A.H.; Gelder, M.G.; Rix, S.; Meltzer, H.I.; and Rowlands, O.J. (2000). Stigmatisation of people with mental illness, *British Journal of Psychiatry*, 177, pp. 4-7.
- Dazord, A. (1997). The Subjective Quality of Life Questionnaire (SQLP): an Updated Review of Validation and Results, *Quality of Life newsletter*, 18, pp. 7-8.
- Dazord, A. (2002). Le concept de qualite de vie, resultats d'enquetes effectuees aupres de 13,000 sujets, *Recherche en Soins Infirmiers*, 70, pp. 23-38.
- Dazord, A. ; Astolfi, F. ; Guisti, P. ; Rebetez, M.C. ; Mino, A. ; Terra, J.L. ; and Brochier, C. (1998). Quality of life assessment in Psychiatry : The Subjective Quality of Life Profile (SQLP) – first results of a new instrument, *Community Mental Health Journal*, 34 (5), 525-535.

- De Haes, J.C.J.M. and van Knippenberg, F.C.E. (1985). The quality of life of cancer patients: a review of the literature. *Social Science and Medicine* 20, pp.809–817.
- Dickerson, F. B.; Sommerville, J.; Origoni, A. E.; Ringel, N. B. ; Parente, F. (2002). Experiences of stigma among outpatients with schizophrenia, *Schizophrenia Bulletin*, 28 (1), pp. 143-155.
- Dickoff, J.; James, P.; and Wiedenbach, E. (1992). Theory in a Practice Discipline. Part I: Practice Oriented Theory. In: Nicoll, L.H. (ed). *Perspectives on Nursing Theory*, 2<sup>nd</sup> edition, pp. 468-500. Lippincott Company, Pennsylvania, USA.
- Diener, E. (1984). Assessing subjective well-being: progress and opportunities, *Social Indicators Research*, 31, pp. 103–157.
- Doyle, M.; Flanagan, S.; and Browne, S. (1999). Subjective and external assessments of quality of life in schizophrenia: relationship to insight, *Acta Psychiatrica Scandinavica*, 99, pp. 466–72.
- Draper, P (1992). Quality of life as quality of being: an alternative to the subject-object dichotomy, *Journal of Advanced Nursing*, 17, pp. 965-970.
- DSM-IV-TR (2000). American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, 4th edn, Washington, DC: APA.



- Ertugrul, A. and Ulu B. (2004). Perception of stigma among patients with schizophrenia, *Social Psychiatry and Psychiatric Epidemiology*, 39 (1), pp. 73-77
- Field, P.A. and Morse, J.M. (1985). *Nursing Research: the Application of Qualitative approaches*. Chapman and Hall, London, UK.
- Fielder, H.; Denholm, S.W.; Lyons, R.A.; and Feilder, C.P. (1996). Measurement of health status in patients with vertigo, *Clinical Otolaryngology and Allied Sciences*, 21 (2), pp. 124-126.
- Fischer, E. P.; Shumway, M.; and Owen R. R. (2002). Priorities of Consumers, Providers, and Family Members in the Treatment of Schizophrenia, *Psychiatric Services*, 53, pp. 724-729.
- Flanagan, J.C. (1978). A research approach to improving our quality of life, *American Psychology*, 33, pp. 138–147.
- Flanagan, J.C. (1982). Measurement of quality of life: current state of the art. *Archives of Physiological and Medical Rehabilitation* , 63, pp. 56–59.
- Fleischhacker, W.W.; Harfner, H.; Leff, J; Lopez-Ibor, J.; Maj, M.; Santorious, N.; Stefanis, C.; Warner, R.; and Wig, N. (1998). The WPA global programme against stigma and discrimination because of schizophrenia, *Schizophrenia Research*, 29 (1), pp. 194-201

- Francis, A. and Papageorgiou, P. (2004). Expressed emotion in Greek versus Anglo-Saxon families of individuals with schizophrenia, Australian Psychologist, 39 (2), pp. 172-177.
- Gaebel, W.; Baumann, A.; Witte, A. M.; and Zaeske H. (2002). Public attitudes towards people with mental illness in six German cities. Results of a public survey under special consideration of schizophrenia, European Archives of Psychiatry and Clinical Neuroscience, 252 (6), pp. 278-287.
- Gaite, L.; Vázquez-Barquero, J. L.; Borra, C.; Ballesteros, J.; Schene, A.; Welcher, B.; Thornicroft, G.; Becker, T.; Ruggeri, M.; Herrán, A.: the EPSILON Study Group (2002). Quality of life in patients with schizophrenia in five European countries: the EPSILON study, Acta Psychiatrica Scandinavica, 105 (4), pp. 283–292.
- Gaite, L.; Vázquez-Barquero, J. L.; Arriaga Arrizabalaga, A.; Vázquez-Bourgon, E.; Retuerto, M. P. (2000). Quality of life in schizophrenia: development, reliability and internal consistency of the Lancashire Quality of Life Profile - European Version - EPSILON Study 8, The British Journal of Psychiatry, 177, pp. s49-s54.
- Galletly, C.A.; Clark, C.R.; McFarlane, A.C.; and Weber, D.L. (1997). Relationships between changes in symptoms ratings, neuropsychological test performance, and quality of life in schizophrenic patients with clozapine, Psychiatry Research, 72, pp.161-166.

- Gee, L.; Pearce, E.; and Jackson, M. (2003). Quality of life in schizophrenia: A grounded theory approach, Health and Quality of Life Outcomes, 1 (31), available at: <http://www.hqlo.com/content/1/1/31>
- Gehrmann, F. (1978). "Valid" empirical measurement of quality of life? Social Indicators Research, 5, pp. 73-109.
- Gerin, P.; Dazord, A.; Boissel, J.; Chifflet, R. (1992). Quality of life assessment in therapeutic trials: rationale for the presentation of a more appropriate instrument, Fundamental and Clinical Pharmacology, 6, pp. 263-276.
- Gerlach, J. and Larsen, E.B. (1999). Subjective experience and mental side-effects of antipsychotic treatment, Acta Psychiatrica Scandinavica, 395, pp. 113-117 Suppl.
- Germain, C. (1986). Ethnography: the method. In: In: Munhall, P.L. and Olier, C.J. (eds), Nursing Research: a qualitative perspective, pp. 147-162, Appleton-Century-Crofts, Norwalk, Connecticut, USA.
- Gerstein, L. H.; Bates, H. D. and Reindl, M. (1987). The experience of loneliness among schizophrenic and normal persons, Journal of Social Behaviour and Personality, 2, pp. 239-248.
- Ghadirian, A.M.; Chouinard, G.; and Annable, L. (1982). Sexual dysfunction and plasma prolactin levels in neuroleptic-treated schizophrenic outpatients, Journal of Nervous and Mental Disease, 170 (8), pp. 463-67.

- Gibbons J.S. and Butler J.P. (1987) Quality of life for 'new' long-stay psychiatric in-patients: the effects of moving to a hostel. British Journal of Psychiatry, 151, pp. 347-354.
- Gill, W.M. (1984). Measuring a patient's quality of life, New Zealand Medical Journal, 97, pp. 329-330
- Glynn, S.M.; Cohen, A.N.; Dixon, L.B.; and Niv, N. (2006). The potential impact of the recovery movement on family interventions for schizophrenia: opportunities and obstacles, Schizophrenic Bulletin, 32 (3), pp. 451-63.
- Green, C.A.; Fenn, D.S.; Mousaoui, D.; Kadri, N.; and Hoffman, W.F. (2001). Quality of life in treated and never treated schizophrenic patients, Acta Psychiatrica Scandinavica, 103, pp. 131-142.
- Guba, E.J. and Lincoln, Y.S. (1989). Fourth Generation Evaluation. Sage Publications, Ltd., California, USA.
- Gumley, A.; Karatzias, A.; Power, K.; Reilly, J.; McNay, L.; and O'Grady, M. (2006). Early intervention for relapse in schizophrenia: impact of cognitive behavioural therapy on negative beliefs about psychosis and self-esteem, British Journal of Clinical Psychology, 45(2), pp. 247-60.

- Haghighat, R. (2001). A unitary theory of stigmatization: pursuit of self-interest and routes to destigmatisation, British Journal of Psychiatry, 178, pp. 207–215.
- Hanley, S. J. and Abell, S. C. (2002). Maslow and Relatedness: Creating an Interpersonal Model of Self-Actualization, Journal of Humanistic Psychology, 42, pp. 37-57
- Hansson, L.; Middelboe, T.; Merinder, L. (1999). Predictors of subjective quality of life in schizophrenic patients living in the community. A Nordic multicentre study. International Journal of Social Psychiatry, 45, pp. 247–258.
- Hansson, L.; Svensson, B.; and Björkman, T. (1998). Quality of life of the mentally ill. Reliability of the Swedish version of the Lancashire Quality of life profile, European Psychiatry, 13 (5), pp. 231-234.
- Harwood, P.L. (1976). Quality of life: Ascriptive and testimonial conceptualizations, Social Indicators Research, 3 (3-4), pp. 471-496
- Hatfield, A.B.; Gearon, J. S.; Coursey, R.D. (1996). Family members' ratings of the use and value of mental health services: results of a national NAMI survey, Psychiatric Services, 47, pp. 825-831.
- Hellzén, O.; Kristiansen L.; Norbergh K.G. (2003). Nurses' attitudes towards older residents with long-term schizophrenia, Journal of Advanced Nursing, 43 (6), pp. 616–622.

- Hewitt, J. (2006). Critical evaluation of the use of research tools in evaluating quality of life for people with schizophrenia, *International Journal of Mental Health Nursing*, 16(1), pp.2-14.
- Ho, B. C.; Nopoulos, P.; Flaum, M.; Arudt, S. and Andreasen, N. C. (1998). Two year outcome in first episode schizophrenia: Predictive value of symptoms for quality of life, *American Journal of Psychiatry*, 155, pp. 1196–1201.
- Holmes, C. A. (1989). Health care and quality of life: A review, *Journal of Advanced Nursing*, 14, pp. 833-839.
- Hörberg, U.; Brunt, D.; Axelsson, A. (2004). Clients' perceptions of client–nurse relationships in local authority psychiatric services: A qualitative study, *International Journal of Mental Health Nursing*, 13 (1), pp. 9–17.
- Hultman, C.M. (1999). Prenatal and perinatal risk factors for schizophrenia, affective psychosis, and reactive psychosis of early onset: case-control study, *British Medical Journal*, 13; 318(7181): 421–426.
- Humberstone, V. (2002). The experiences of people with schizophrenia living in supported accommodation: a qualitative study using grounded theory, *Australian and New Zealand Journal of Psychiatry*, 36, pp. 367–372.

- Huppert, J.D.; Kim A.; Weiss, R. L.; Pratt, S.; Smith, T. E. (2001). Quality of life in schizophrenia: contributions of anxiety and depression, Schizophrenia Research , 51, Issues 2-3, pp. 171-180.
- Hutchinson, S. (1986). Grounded Theory: the method. In: Munhall, P.L. and Olier, C.J. (eds), Nursing Research: a qualitative perspective, pp. 111-130, Appleton-Century-Crofts, Norwalk, Connecticut, USA.
- Huxley, P. and Warner, R. (1992). Case management, quality of life, and satisfaction with services of long-term psychiatric patients, Hospital Community Psychiatry, 43, pp. 799–802.
- ICD-10 classification of mental and behavioural disorders (1993) .World Health Organization: The. Diagnostic criteria for research, Geneva, World Health Organization (also available from: <http://www.hqlo.com/content/1/1/31>).
- Jasper M. A. (1994). Issues in phenomenology for researchers of nursing, Journal of Advanced Nursing, 19 (2), pp. 309–314.
- Jenkinson, C.; Wright, L.; and Coulter, A. (1994). Criterion validity and reliability of the SF-36 in a population sample, Quality of Life Research, 3, pp.7-12.
- Johnson, R.B. and Onwuegbuzie, A.J. (2004). Mixed methods research: a research paradigm whose time has come, Educational Researcher, 33 (7), pp: 14-26.

- Kaiser, W.; Priebe, S.; Barr, W.; Hoffmann, K.; Isermann, M.; Röder-Wanner, U.U.; and Huxley, P. (1997). Profiles of subjective quality of life in schizophrenic in- and out-patient samples, *Psychiatry Research*, 66, pp. 153–166.
- Kane, J.; Honigfeld, G.; Singer, J.; Meltzer, H. (1988). Clozapine for the treatment- resistant schizophrenic: a double-blind comparison with chlorpromazine, *Achieves in General Psychiatry*, 45, pp. 789–796.
- Karastergiou, A.; Mastrogianni, A.; Georgiadou, E.; Kotrotsios, S.; and Mauratziotou, K. (2005). The reform of the Greek mental health services, *Journal of Mental Health*, 14 (2), pp. 197 – 203.
- Keks, N. A. (1997). Impact of newer antipsychotics on outcomes in schizophrenia, *Clinical Therapeutics*, 19, pp. 148–158.
- Kelly, D. L. and Conley, R. R. (2004). Sexuality and Schizophrenia: A Review, *Schizophrenia Bulletin*, 30(4), pp. 767-779.
- Kemmler, G.; Holzner, B.; Neudorfer, C.; Meise, V.; and Hinterbuber, H. (1997). General life satisfaction and domain specific quality of life in chronic schizophrenic patients, *Journal of Quality of Life*, 6, pp. 265–273.
- Kendell, R. E. (2001). The distinction between mental and physical illness, *The British Journal of Psychiatry*, 178, pp. 490-493.
- Kennedy J L; Giuffra L A; Moises H W; Cavalli-Sforza L L; Pakstis A J; Kidd J R; Castiglione C M; Sjogren B; Wetterberg L; Kidd K K (1978)



- Evidence against linkage of schizophrenia to markers on chromosome 5 in a northern Swedish pedigree, Nature, 336 (6195), pp. 167-70.
- Knudsen, H.C.; Vazquez-Barquero, J.L.; Welcher, B.; Gaité, L.; Becker, T.; Chisholm, D.; Ruggeri, M.; Schene, A.H.; Thornicroft, G.; and the EPSILON study group (2000). Translation and cross-cultural adaptation of outcome measurements for schizophrenia, British Journal of Psychiatry, 177(39): pp. 8 - 14 supplement.
- Koivisto, K.; Janhonen, S.; and Väisänen, L. (2002). Applying a phenomenological method of analysis derived from Giorgi to a psychiatric nursing study, Journal of Advanced Nursing, 39 (3), pp. 258-265.
- Kreiger, N. and Fee, E. (1994). Man-made medicine and women's health: The biopolitics of sex/gender and race/ethnicity, International, Journal of Health Services, 24 (2), pp. 265-283.
- Kumra, S.; Frazier, J.A.; Jacobsen, L.K.; McKenna, K.; Gordon, C.T.; Lenane, M.C.; Hamburger, S.D.; Smith, A.K.; Albus, K.E.; Alaghband-Rad, J.; Rapoport, J.L. (1996). Childhood-onset schizophrenia: a doubleblind clozapine-haloperidol comparison, Archives in General Psychiatry, 53, pp. 1090–1097.

- Kuyken, W.; Orley, J.; Hudelson, P.; and Sartorius, N. (1994). Quality of life assessment across cultures, International Journal of Mental Health, 23 (2), pp. 5-27.
- Kuzel, A. J. (1998). Naturalistic Inquiry: An Appropriate Model for Family Medicine, Family Medicine, 30 (9), pp. 665-71.
- Laborde J.M. and Powers M.J. (1980) Satisfaction with life for patients undergoing haemodialysis and patients suffering from osteoarthritis, Research in Nursing and Health, 3, pp. 19-24.
- Larsen, E.B. and Gerlach, J. (1996). Subjective experience of treatment, side-effects, mental state and quality of life in chronic schizophrenic out-patients treated with depot neuroleptics, Acta Psychiatrica Scandinavica, 93 (5), pp. 381-388.
- Larson, R. (1978). Thirty years of research on the subjective well-being of older Americans, Journal of Gerontology, 33, pp. 109–125.
- Lee, P.; Whitcup, S.; Hays, R.; Spritzer, K.; and Javitt, J. (1995). The relationship between visual acuity and functioning and well-being among diabetics, Qualification Life Research, 4 (4), pp. 319-323.
- Leff, J. (1998). The influence of discrimination and stigma on the life of patients and their relatives, European Psychiatry, 13 (4), p. 163supplement.

- Leff, J.; Dayson, D.; Gooch, C.; Thornicroft, G.; and Wills, W. (1996). Quality of life of Long-stay patients discharged from two psychiatric institutions, Psychiatric Services, 47 (1), pp. 62-67.
- Lehman, A. F. and Steinwachs, D. M. (1998). Patterns of usual care for schizophrenia: Initial results from the Schizophrenia Patient Outcomes Research Team (PORT) client survey, Schizophrenia Bulletin, 24 (1), pp. 11-20
- Lehman, A.F. (1983). The well-being of chronic mental patients, Archives of General Psychiatry 40, pp. 369-374.
- Lehman, A. F.; Kernan, E.; DeForse, B. R.; and Dixon, L. (1995). Effects of homelessness on the quality of life of persons with severe mental illness, Psychiatric Services, 46, pp. 522-526.
- Lehman, A.F.; Possidente, S.; and Hawker, F. (1986). The quality of life of chronic patients in a state hospital and in community residences, Hospital Community Psychiatry, 37, pp. 901-907.
- Lehman, A.F.; Slaughter, J.C. ;and Myers, C.P. (1991). The quality of life of chronically mentally ill persons in alternative residential settings, Psychiatry Quarterly, 62, pp. 35-49.
- Lehman, A.F.; Slaughter, J.C. ;and Myers, C.P. (1992). The quality of life of chronically mentally ill: Gender and decade of life effects, Evaluation and Program Planning, 15, pp. 7-12

Lehman, A.F.; Ward, N.C. and Linn, L.S. (1982). Chronic mental patients: The quality of life issue, American Journal of Psychiatry, 10, pp. 1271–1276.

Leibe, M. and Kallert, T.W. (2000). Social integration and the quality of life of schizophrenic patients in different types of complementary care, European Psychiatry, 15, pp. 450–460.

Leininger, M. (1985). Qualitative Research Methods in Nursing. Grune and Stratton, Inc., Florida, USA.

Leininger, M. (1994). Evaluation criteria and critique of quantitative studies. In: Morse, J. (ed.) Clinical Issues in Qualitative Research. Thousand Oaks: Sage.

Link, B. G.; Struening, E. L.; Rahav, M.; Phelan, J. C.; and Nuttbrock, L. (1997). On Stigma and Its Consequences: Evidence from a Longitudinal Study of Men with Dual Diagnoses of Mental Illness and Substance Abuse, Journal of Health and Social Behaviour, 38 (2), pp. 177–190.

Liu, B. (1974). Quality of life indicators: A preliminary investigation, Social Indicators Research, 1, pp. 187–208.

Lutjens, L.R.J. (1995). Martha Rogers: The Science of Unitary Human Beings. In McQuiston and Webb, A.A. (eds), Foundations of Nursing Theory, SAGE publications, Inc.

- Lysaker, P., and Bell, M. (1995). Work performance over time for people with schizophrenia, *Psychosocial Rehabilitation Journal*, 18, pp.141-145.
- MacGilp, D. (1991). A quality of life study of discharged long-term psychiatric patients, *Journal of Advanced Nursing*, 16, pp. 1206-1215.
- Madianos, M. (1994). Recent advances in community psychiatry and psychological rehabilitation in Greece and the other southern European countries, *International Social Psychiatry*, 40, pp. 157-164.
- Madianos, M. G.; Zachariadis, C.; Tsitsa, C.; and Stefanis, C. (1999). The mental health delivery system in Greece: regional variation and socioeconomic correlates, *The Journal of Mental Health Policy and Economics*, 2, pp. 169-176.
- Maggs-Rapport, F. (2000). Combining methodological approaches in research: ethnography and interpretive phenomenology, *Journal of Advanced Nursing*, 31 (1), pp. 219-225.
- Malm, U.; May, P.R.A.; and Dencker, S.J. (1981). Evaluation of the quality of life of the schizophrenic outpatient: a checklist, *Schizophrenia Bulletin*, 7, pp. 477-487.
- Marwaha, S.; Johnson, S.; Bebbington, P.; Stafford, M.; Angermeyer, M.C.; Brugha, T.; Azorin, J.M.; Kilian, R.; Hansen, K.; and Toumi, M. (2007). "Rates and correlates of employment in people with schizophrenia in the UK, France and Germany", *British Journal of Psychiatry*, 191, pp. 30-37

- Mays, N. and Pope, C. (1995). Qualitative Research: Rigour and qualitative research, *British Medical Journal*, 311, pp. 109-112.
- McCabe, C.J.; Thomas, K.J.; Brazier, J.E.; and Coleman, P. (1996). Measuring the mental health status of a population: A comparison of the GHQ-12 and the SF-36 (MHI-5), *British Journal of Psychiatry*, 169 (4), pp. 516-521.
- McCall, S. (1975). Quality of Life, *Social Indicators Research*, 2, pp 229-248
- McCallum, J. (1995). The SF-36 in an Australian sample: Validating a new, generic health status measure, *Australian Journal of Public Health*, 19(2), pp. 160-167.
- McDonald, J. and Badger, T. (2002). Social function of persons with schizophrenia, *Journal of Psychosocial Nursing and Mental Health Services*, 40 (6), pp. 42–50.
- McDonald, S.; Halliday, J.; MacEwan, T.; Sharkey, V.; Farrington, S.; Wall, S.; and McCreddie, G. (2003). Nithsdale Schizophrenia Surveys 24: sexual dysfunction, *The British Journal of Psychiatry*, 182, pp. 50-56.
- McEvoy, P. and Richards, D. (2006). Critical realism: a way forward for evaluation research in nursing? *Journal of Advanced Nursing*, 43 (4), pp: 411-420.
- McFarlane, W.R.; Lukens, E.; Link, B.; (1995). Multiple-family groups and psychoeducation in the treatment of schizophrenia, *Archives of General Psychiatry*, 52, pp.679-687.

- McGrath, J. J. (2006). Variations in the Incidence of Schizophrenia: Data Versus Dogma, Schizophrenia Bulletin, 32, 1, pp. 195-197
- McGrath, J.; Saha, S.; Welham, J.; El Saadi, O.; MacCauley, C.; and Chant, D. A. (2004) Systematic review of the incidence of schizophrenia: the distribution of rates and the influence of sex, urbanicity, migrant status and methodology, British Medical Journal, 2, pp. :113, available at: <http://www.ncbi.nlm.nih.gov/pubmed/15115547?dopt>
- McKennell, A.C. (1978). Cognition and affect in perceptions of well-being, Social Indicators Research, 5, pp. 389-426.
- McNally S. and Goldberg J.1997. Natural cognitive coping strategies in schizophrenia, British Journal of Medical Psychology, 70, pp. 159–167.
- Meijer, C.J. (2002). Quality of life in schizophrenia measured by the MOS SF-36 and the Lancashire Quality of Life Profile: a comparison, Acta Psychiatrica Scandinavica, 105, pp. 293-300.
- Moberg, D.O. and Brusek, P.M. (1978). Spiritual well-being: A neglected subject in quality of life research, Social Indicators Research, 5 (1-4), pp. 303-323.
- Monti, A.J. and Tingen, M.S. (1999). Multiple paradigms of nursing science, Advances in Nursing Science, 21 (4), pp. 64-80.

- Morgan, R. and Gopalaswamy, A. K. (1983) Employability of the mentally disabled in the 1970s, British Journal of Psychiatry, 142, pp. 572 -574
- Morganstern, H. and Glazer, W. (1993). Identifying risk factors for tardive dyskinesia among chronic outpatients maintained on neuroleptic medications: results of the Yale Tardive Dyskinesia Study, Archives in General Psychiatry, 50, pp. 723–733.
- Morse, J.M. and Field, P.A. (1996). Qualitative approaches. In: Nursing Research. The application of qualitative approaches, 2<sup>nd</sup> edition, pp. 124-140. Stanley Thornes. Ltd
- Mowbray, C.T.; Bybee, D.; Harris, S.; McCrohan, N. (1995). Predictors of work status and future work orientation in people with a psychiatric disability, Psychiatric Rehabilitation Journal, 19, pp.17-28.
- Moyle W. (2003). Nurse–patient relationship: A dichotomy of expectations, International Journal of Mental Health Nursing 12, pp. 103–109.
- Mubarak, A.R.; Baba, I.; Chin, L.H.; and Hoe, Q.S. (2003). Quality of life of community based chronic schizophrenia patients in Penang, Malaysia, Australian and New Zealand Journal of Psychiatry, 37, pp. 577-585.
- Muijen, M. (1996). Hospital care: from sun to moon, European Psychiatry, 11 (1004), p. 189s.



- Muir-Cochrane E. (2001). The case management practices of community mental health nurses: 'Doing the best we can', *Australian and New Zealand Journal of Mental Health Nursing*, 10 (4), pp. 210–220.
- Najman, J.M. and Levine, S. (1981).Evaluating the impact of medical care and technologies on the quality of life: a review and critique, *Social Science Medicine*, 15, pp. 107-115.
- Nicoll, L.H. (1992). *Perspectives on Nursing Theory*, 2<sup>nd</sup> edition. Lippincott Company, Pennsylvania, USA.
- Nisson, L. L. and Levander, S. (1998). Quality of life in schizophrenia, *Nordic Journal of Psychiatry*, 52, pp. 277–283.
- Norman, R.M.G.; Mall, A.K.; McLean, T.; Voruganti, L.P.N.; Cortese, L.; McIntosh, E.; Cheng, S.; and Rickwood, A. (2000). The relationship of symptoms and level of functioning in schizophrenia to general well-being and the quality of life scale, *Acta Psychiatrica Scandinavica*, 102, pp. 303-309.
- Okin, R.L.; Dolnick, J.A.; and Pearsall, D.T. (1983). Patients' perspectives on community alternatives to hospitalization: a follow-up study, *American Journal of Psychiatry*, 140, pp. 1460-1464.
- Oliver, J.; Huxley, P.; Bridges, K.; and Mohabad, H. (1996). *Quality of life and mental health services*. London: Routledge.

Oliver, J.; Huxley, P.; Priebe, S. (1997). Measuring the quality of life of severely ill people using the Lancashire Quality of Life Profile, *Social Psychiatry and Psychiatric Epidemiology*, 32, 76 -83.

Padilla G.V.; Ferrell B.; Grant M.M.; and Rhiner M. (1990) Defining the content domain of quality of life for cancer patients with pain, *Cancer Nursing*, 13, pp. 108 115.

Parahoo, K. (2006). *Nursing Research Principles, Process and Issues*, 2<sup>nd</sup> edition, Palgrave MacMillan Publications.

Parashos, J. (1998). *Athenians' views on mental and physical illness*, Athens, Lundbeck, Hellas

Parse, R.R. (1995). *Illuminations: The human becoming theory in practice and research*, National League for Nursing, New York.

Parse, R.R.; Coyne, A.B.; and Smith, M.J. (1985). *Nursing Research: Qualitative Methods*. Prentice-Hall, Maryland, USA.

Patterson, T.; Semple, S.J.; Shaw, W.S.; Halpain, M.; Moscona, S.; Grant, I.; and Jeste, D.V. (1997). Self-reported social functioning among older patients with schizophrenia, *Schizophrenia Research*, 27, pp. 199-210.

Pedersen, C. B. and Mortensen, P. B. (2001). Family history, place and season of birth as risk factors for schizophrenia in Denmark: a

- replication and reanalysis, *The British Journal of Psychiatry*, 179, pp. 46-52.
- Penn, D.; Kohlmaier, J. and Corrigan, P. (2000). Interpersonal factors contributing to the stigma of schizophrenia: social skills, perceived attractiveness, and symptoms, *Schizophrenia Research*, 45, PP. 37-45.
- Pidgeon, N. (1996). Grounded Theory: theoretical background. In Richardson, JTE ed. *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*, British Psychological Society Books; pp. 75-85.
- Polit, D.F. and Hungler, B.P. (1995). *Nursing Research. Principles and Methods*, 5<sup>th</sup> ed., J.B. Lippincott, Philadelphia, USA.
- Polit, D.F.; Beck, C.T.; and Hungler, B.P. (2001). *Essentials of Nursing Research. Methods, appraisal and utilisation*, 5<sup>th</sup> edition. Lippincott, PA, USA.
- Pope, C and Mays, N. (2006). *Qualitative Research in Health Care*, 3<sup>rd</sup> edition, Blackwell Publishing.
- Pope, C.; Ziebland, S.; Mays, N. (2000). Qualitative research in health care: Analysing qualitative data, *British Medical Journal*, 320, pp. 114-116

- Priebe, S.; Roeder-Wanner, U.U.; and Kaiser, W. (2000). Quality of life in first admitted schizophrenia patients: a follow-up study, *Psychological Medicine*, 30 (1), pp. 225-230.
- Priebe, S.; Warner, R.; Hubschmid, T.; Eclde, I. (1998). Employment, Attitudes Toward Work, and Quality of Life Among People With Schizophrenia in Three Countries, *Schizophrenia Bulletin*, 24 (3), pp. 469-477.
- Report to the UK Department of Health (2000, Sept.). National Centre for Health Outcomes Development, University of Oxford. Patient-reported Health Instruments Group.
- Revicki, D.A.; Genduso, L. A.; Hamilton, S. H.; Ganoczy, D.; and Beasley, C. M. (1999). Olanzapine versus haloperidol in the treatment of schizophrenia and other psychotic disorders: Quality of life and clinical outcomes of a randomized clinical trial, *Quality of life Research*, 8 (5), PP. 417-426.
- Ritsner, M.; Gibel, A.; and Ratner, Y. (2006). Determinants of changes in perceived quality of life in the course of schizophrenia, *Quality of Life Research*, 15, pp. 515-526.
- Ritsner, M.S. (2007). Predicting quality of life impairment in chronic schizophrenia from cognitive variables, *Quality of Life Research*, 16 (6), pp. 929-937

- Rodner-Wanner, U.; Oliver, J.; and Priebe, S. (1997). Does quality of life differ in schizophrenic women and men? An empirical study, *International Journal of Social Psychiatry*, 43, pp. 129-143.
- Romney, D. M. and Evans, D.R. (1996). Toward a general model of health-related quality of life, *Quality of Life Research*, 5 (2), pp. 235-241.
- Rosen, A. (2003). What developed countries can learn from developing countries in challenging psychiatric stigma, *Australian Psychiatry*, 11, pp. s89-s95.
- Rosenfield, S. (1992). Factors contributing to the subjective quality of life of the chronically mentally ill, *Journal of Health and Social Behaviour*, 33, pp. 299-315.
- Rosenfield, S. And Neese-Todd, S. (1993). Elements of a psychosocial clubhouse program associated with a satisfying quality of life, *Hospital and Community Psychiatry*, 44, pp. 76-78.
- Rosenheck, R.; Leslie, D.; Keefe, R.; McEvoy, J.; Swartz, M.; Perkins, D.; Stroup, S.; Hsiao, J.K.; Lieberman J. (2006). Barriers to Employment for People with Schizophrenia, *American Journal of Psychiatry*, 163, pp.411–417.
- Rossler, W. (1997). Perspectives of the organisation of mental health care in Europe, *European Psychiatry*, 2, p. 109s.

- Rossler, W.; Salize, H.J.; Cucchiaro, G.; Reinhard, I.; and Kerling, C. (1999). Does the place of treatment influence the quality of life of schizophrenics? Acta Psychiatrica Scandinavica, 100, pp. 142-148.
- Ruggeri, M.; Gater, R.; Bissoffi, G.; Barbui, G.; and Tansella, . (2002). Determinants of subjective quality of life in patients attending community-based mental health services. The South-Verona Outcome Project 5, Acta Psychiatrica Scandinavica, 105 (2), pp. 131-140.
- Rüsch, N.; Lieb, K.; Bohus, M.; and Corrigan, P.W. (2006). Self-Stigma, Empowerment, and Perceived Legitimacy of Discrimination Among Women With Mental Illness, Psychiatric Services, 57 (3), pp.399-402.
- Russo, J; Trujillo, C. A.; Wingerson, D.; Decker, K.; Ries, R.; Wetzler, H.; and Roy-Byrne, P. (1998). The MOS 36-Item Short Form Health Survey: Reliability, Validity, and Preliminary Findings in Schizophrenic Outpatients, Medical Care, 36 (5), pp.752-756.
- Sandelowski, M. (2000). Combining quantitative and qualitative sampling, data collection, and analysis techniques in mixed-method studies, Research in Nursing and Health, 9, pp. 279-287.
- Sartorius, N. (1998). Stigma: what can psychiatrists do about it? Lancet, 352, pp. 1058-1059.
- Sciolla, A.; Patterson, T.L.; Loebach, J.; McAdams, L. ; and Jeste, D. (2003). Functioning and well-being of middle-aged and older people with schizophrenia. Measurement with the 36-item short-form (SF-36)

- Health Survey, American Journal of Geriatric Psychiatry, 11, pp. 629-637.
- Schultz, G. S. and Cobb-Stevens, R. (2004). Husserl's theory of wholes and parts and the methodology of nursing research, Nursing Philosophy, 5, pp. 216–223.
- Schulze, B. and Angermeyer, M. (2003). Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals, Social Science and Medicine, 56, pp. 299-312.
- Simons, L. (2007). Moving from collision to integration. Reflecting on the experience of mixed methods, Journal of Research in Nursing, 12 (1), pp. 73-83.
- Simpson, C.J.; Hyde, C.E.; and Faragher, B. (1989). The chronically mentally ill in community facilities. A study of quality of life, British Journal of Psychiatry, 154, pp. 77-82.
- Sims, J. and Snell, J. (1996). Focus groups in physiotherapy evaluation research, Physiotherapy, 82 (3), pp. 256-261.
- Skantze, K., Malm, U., Dencker, S. J., May, P. R. & Corrigan, P. (1992). Comparison of quality of life with standard living of schizophrenic outpatients, British Journal of Psychiatry, 161, 797-801

- Stefanis C., Madianos M.G. ; and Gittelman M. (1986). Recent developments in the care, treatment and rehabilitation of the chronic mentally ill in Greece, Hospital Community Psychiatry, 37, pp. 1041–1044.
- Stern, P. N. (1985). Using grounded theory in nursing research. In: Leininger, M. (ed). Qualitative Research Methods in Nursing (pp. 149-160). Grune and Stratton, Inc., Florida, USA.
- Stevens, P. J. M.; Schade, A. L.; Chalk, B.; and Slevin, O.D.A. (1993). Understanding Research: A Scientific Approach for Health Care Professionals. Campion Press, Edinburgh, UK.
- Sullivan, G. and Lukoff, D. (1990). Sexual side effects of antipsychotic medication: Evaluation and interventions, Hospital Community Psychiatry, 41, pp. 1238-1241.
- Swanson-Kauffman, K. and Schonwald, E. (1988). Phenomenology. In: Sarter, B. (ed), Paths to Knowledge. National League for Nursing, N.Y., USA
- Tansella, M. (1996). Community-based psychiatric care without back-up from the mental hospital. A long-term experience, European Psychiatry, 11 (1004), p. 189 s.
- Tountas, Y.; Demakakos, P.T.; Yfantopoulos, Y.; Aga, J.; Houliara L.; Pavi, E. (2003). The health related quality of life of the employees in the Greek hospitals: assessing how healthy are the health workers,



Health and Quality of Life Outcomes, 1(61), <http://www.hqlo.com/content/1/1/61>.

Treece, E.W. and Treece, J.W. (1986). Elements of research in nursing, 4<sup>th</sup> edition. The CV Mosby Company, St Louis, Missouri, USA.

Tritsch, J.M. (1998). Application of King's Theory of Goal Attainment and the Carondelet St. Mary's Case Management Model, Nursing Science Quarterly, 11(2), pp: 69-73.

Tyrer, P. (2000) The future of the community mental health team, International Review of Psychiatry, 12 (3), pp. 219 – 225.

Van Der Zalm J.E. and Bergum V. (2000). Hermeneutic-phenomenology: providing living knowledge for nursing practice, Journal of Advanced Nursing 31(1), pp. 211-218.

Van Dongen C.J. (1998). Self – esteem among persons with severe mental illness, Issues in Mental Health Nursing, 19 (1), pp. 29 – 40

Van Manen, M. (1990). Researching the lived experience. Albany: State University of New York Press.

Van Nieuwenhuizen, C.; Schene, A.; Boevink, W; Wolf, J. (1998). The Lancashire Quality of Life Profile: first experiences in the Netherlands, Community Mental Health Journal, 34 (5), pp: 513-524.

- Vandiver, V.L. (1998). Quality of life, gender and schizophrenia: a cross-national survey in Canada, Cuba, and U.S.A., Community Mental Health Journal, 34, pp. 501-511.
- Veenhoven, R. 1991 Is happiness relative? Social Indicators Research, 24 (1), pp. 1-34
- Voruganti, L. N. P. and Awad, A. G. (2002). Personal evaluation of transitions in treatment (PETiT):a scale to measure subjective aspects of antipsychotic drug therapy in schizophrenia, Schizophrenia Research, 56, Issues 1-2, pp. 37-46.
- Wanner,V. R., Joseph,P. J., Oliver,J. & Priebe,S. (1997). Does quality of life differ in schizophrenic women and men? An empirical study, International Journal of Social Psychiatry, 43, pp. 129–143.
- Ware, J. and Sherbourne, C. (1992) The MOS, 36-item Short-Form Health Survey (SF-36): conceptual framework and item selection, Medical Care, 30, pp. 473-483.
- Warner, R.; Girolamo, G. D.; Belelli, G.; Bologna, C.; Fioritti, A.; and Rosini, G. (1998). The quality of life of people with schizophrenia in Boulder, Colorado and Bologna, Italy, Schizophrenia Bulletin, 24, pp. 559–568.
- Whitty, P. ; Browne, S.; Clarke, M.; McTigue, O.; Waddington, J.; Kinsella, T.; Larkin, C.; and O'Callaghan, E. (2004). Systematic Comparison of Subjective and Objective Measures of Quality of Life at 4-Year Follow-

Up Subsequent to a First Episode of Psychosis, Journal of Nervous & Mental Disease, 192(12), pp. 805-809.

Wilkinson, G.; Hesdon, B.; Wild, D.; Cookson, R.; Farina, C.; Sharma, V.; Fitzpatrick, R.; and Jenkinson, C. (2000). Self-report quality of life measure for people with schizophrenia: the SQLS, British Journal of Psychiatry, 177, pp. 42-46.

Wilkinson, G.; Piccinelli, M.; Falloon, I.; Krekurian, H.; and McLees, S. (1995). An evaluation of community-based psychiatric care for people with treated long-term mental illness, British Journal of Psychiatry, 167, pp. 26-37.

Yegdich T. (2000). In the name of Husserl: nursing in pursuit of the things-in-themselves, Nursing Inquiry, 7 (1), pp. 29-40.

Young, A.S; Sullivan, G.; Burnam, M.A.; and Brook, R.H. (1998). Measuring the quality of outpatient treatment for schizophrenia, Archives of General Psychiatry, 55, pp. 611-617.

Yutaka, O.; Satsumi, Y.; Kim, Y.; Iwadate, T.; Moriyama, K.; Nakane, Y.; Nakata, T.; Okagami, K.; Sakai, T.; Sato, M.; Someya, T.; Takagi, S.; Ushijima, S.; Yamauchi, K. and Yoshimura, K. (1999). Schizophrenia: is it time to replace the term? Psychiatry and Clinical Neuroscience, 53, pp. 335-341.

Zautra, A.J. and Hempel, A. (1984). Subjective well-being and physical health: a narrative literature review with suggestions for future research, International Journal of Aging and Human Development, 19 (2), pp.91-110.

Zissi, A.; Barry, M. M.; and Cochrane, R. (1998). A meditational model of quality of life for individuals with severe mental health problems, Psychological Medicine, 28, pp. 1221-1230.

## **APPENDIX A**

### **CONSENT FORM**

I hereby consent to be interviewed by Panagiota Dimitriou for the purposes of the research as explained in the information sheet.

I understand that my identity will not be disclosed. I have the right to refuse to participate and to withdraw from this research at any time though out the study, if I want so.

Data obtained from me will be used for this study only and may be used in future academic publishing purposes. If I need any further information I am free to contact the researcher Panagiota Dimitriou.

Signature.....

Date.....

## **INFORMATION SHEET**

This research is conducted to explore the meaning of quality of life for schizophrenic outpatients living in the community in Greece. Schizophrenic patients who participate in this research will be given a verbal explanation of the study and a copy of the consent form.

The purpose of the research is to help mental health professionals understand the meaning of quality of life as lived by the schizophrenic patients living in the community and to make them aware of the schizophrenic patients' who live in the community experience of quality of life.

The research is conducted by Panagiota Dimitriou.

Questions about the project will be answered to your satisfaction.

Participation requires talking with the researcher on tape about your quality of life for about an hour. The researcher may return to ask for clarification at a later date.

You may withdraw from the study at any time without any consequences.

A tape recorder will be use during the interview and the tape will be destroyed after the project is completed. You are free not to answer any question in order to protect privacy. You may stop the interview or discontinue your participation if discomfort develops during the interview. No last names will appear on the written transcriptions, reports or published papers.

The researcher can be contucted at : 210 9963576 at any time.

Signature.....

Date.....

## **APPENDIX B**

### **Detailed statistical results**

**Table 18**

#### **Factor analysis for satisfaction of core questions**

<b>Component</b>	<b>Initial Eigenvalues</b>			<b>Extraction Sums of Squared Loadings</b>		
	<b>Total</b>	<b>% of Variance</b>	<b>Cumulative %</b>	<b>Total</b>	<b>% of Variance</b>	<b>Cumulative %</b>
1	17.037	68.149	68.149	17.037	68.149	68.149
2	2.308	9.232	77.380	2.308	9.232	77.380
3	2.162	8.647	86.028	2.162	8.647	86.028
4	1.039	4.156	90.183	1.039	4.156	90.183
5	.739	2.957	93.140			
6	.663	2.652	95.793			
7	.561	2.243	98.036			
8	.310	1.242	99.278			
9	.180	.721	99.999			
10	6.21E-005	.000	99.999			
11	5.31E-005	.000	99.999			
12	4.27E-005	.000	99.999			
13	3.80E-005	.000	99.999			
14	3.19E-005	.000	99.999			
15	2.83E-005	.000	100.000			
16	2.23E-005	8.92E-005	100.000			
17	1.76E-005	7.04E-005	100.000			
18	1.51E-005	6.03E-005	100.000			
19	1.38E-005	5.51E-005	100.000			
20	1.24E-005	4.95E-005	100.000			
21	1.03E-005	4.12E-005	100.000			
22	8.18E-006	3.27E-005	100.000			
23	6.77E-006	2.71E-005	100.000			
24	6.27E-006	2.51E-005	100.000			
25	4.57E-006	1.83E-005	100.000			

Extraction Method: Principal Component Analysis.

**Table 19****Component Matrix(a)**

	Component			
	1	2	3	4
q1anew	-.084	.428	.715	-.044
q2anew	-.082	.383	.729	.064
q3anew	-.060	.173	.637	-.087
q4anew	.069	.539	.434	.016
q5anew	.600	.676	-.369	.191
q6anew	.601	.675	-.370	.192
q7anew	.601	.676	-.369	.191
q8anew	.925	.097	-.051	-.334
q10anew	.925	.096	-.051	-.334
q11anew	.925	.097	-.051	-.334
q12anew	.924	.097	-.050	-.334
q13anew	.925	.097	-.051	-.334
q14anew	.876	-.114	.046	-.010
q15anew	.974	-.108	.062	-.004
q16anew	.974	-.107	.063	-.004
q18anew	.974	-.107	.063	-.004
q19anew	.974	-.108	.062	-.004
q20anew	.974	-.108	.062	-.004
q21anew	.974	-.108	.062	-.004
q22anew	.974	-.107	.062	-.004
q23anew	.922	-.172	.122	.267
q24anew	.922	-.171	.123	.267
q25anew	.922	-.172	.122	.267
q26anew	.922	-.172	.121	.267
q27anew	.922	-.172	.121	.267

Extraction Method: Principal Component Analysis.

a 4 components extracted.



**Table 20**

**Factor analysis perceived importance of core questions**

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	17.089	68.357	68.357	17.089	68.357	68.357
2	2.345	9.380	77.737	2.345	9.380	77.737
3	1.668	6.672	84.409	1.668	6.672	84.409
4	1.057	4.227	88.636	1.057	4.227	88.636
5	.929	3.715	92.351			
6	.774	3.098	95.449			
7	.544	2.174	97.623			
8	.459	1.838	99.461			
9	.135	.539	99.999			
10	2.77E-005	.000	100.000			
11	2.47E-005	9.87E-005	100.000			
12	1.31E-005	5.24E-005	100.000			
13	1.15E-005	4.62E-005	100.000			
14	1.10E-005	4.41E-005	100.000			
15	8.98E-006	3.58E-005	100.000			
16	8.76E-006	3.51E-005	100.000			
17	6.58E-006	2.63E-005	100.000			
18	6.19E-006	2.48E-005	100.000			
19	5.19E-006	2.08E-005	100.000			
20	4.94E-006	1.97E-005	100.000			
21	4.12E-006	1.65E-005	100.000			
22	3.53E-006	1.41E-005	100.000			
23	2.88E-006	1.15E-005	100.000			
24	2.65E-006	1.06E-005	100.000			
25	1.68E-006	6.71E-006	100.000			

Extraction Method: Principal Component Analysis.

**Table 21****Component Matrix(a)**

	Component			
	1	2	3	4
q1bnew	.042	-.414	.622	.113
q2bnew	.044	-.455	.673	-.151
q3bnew	.149	-.118	.594	.161
q4bnew	-.020	.145	-.450	.365
q5bnew	.600	.732	.233	-.194
q6bnew	.599	.732	.233	-.193
q7bnew	.599	.732	.233	-.195
q8bnew	.925	.100	.077	.304
q10bnew	.925	.101	.075	.304
q11bnew	.925	.100	.077	.304
q12bnew	.925	.100	.077	.303
q13bnew	.925	.100	.077	.304
q14bnew	.974	-.115	-.060	.002
q15bnew	.974	-.114	-.060	.002
q16bnew	.974	-.115	-.060	.002
q18bnew	.974	-.115	-.060	.002
q19bnew	.974	-.114	-.061	.002
q20bnew	.974	-.114	-.061	.002
q21bnew	.974	-.115	-.060	.002
q22bnew	.974	-.114	-.061	.002
q23bnew	.922	-.182	-.103	-.234
q24bnew	.922	-.182	-.104	-.234
q25bnew	.922	-.182	-.104	-.234
q26bnew	.845	-.190	-.090	-.263
q27bnew	.922	-.182	-.104	-.234

Extraction Method: Principal Component Analysis.  
a. 4 components extracted.

**Table 22****Factor analysis expectation of change of core questions**

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	16.913	67.653	67.653	16.913	67.653	67.653
2	2.660	10.639	78.292	2.660	10.639	78.292
3	1.850	7.401	85.692	1.850	7.401	85.692
4	1.043	4.173	89.866	1.043	4.173	89.866
5	.717	2.866	92.732			
6	.633	2.532	95.264			
7	.561	2.244	97.508			
8	.387	1.548	99.056			
9	.236	.944	100.000			
10	1.73E-005	6.92E-005	100.000			
11	1.29E-005	5.15E-005	100.000			
12	1.01E-005	4.04E-005	100.000			
13	9.24E-006	3.70E-005	100.000			
14	7.76E-006	3.10E-005	100.000			
15	6.21E-006	2.49E-005	100.000			
16	5.26E-006	2.10E-005	100.000			
17	4.91E-006	1.97E-005	100.000			
18	3.99E-006	1.60E-005	100.000			
19	3.03E-006	1.21E-005	100.000			
20	2.88E-006	1.15E-005	100.000			
21	2.60E-006	1.04E-005	100.000			
22	2.23E-006	8.92E-006	100.000			
23	2.16E-006	8.66E-006	100.000			
24	1.84E-006	7.37E-006	100.000			
25	1.15E-006	4.62E-006	100.000			

Extraction Method: Principal Component Analysis.

**Table 23****Component Matrix(a)**

	Component			
	1	2	3	4
q1cnew	-.120	.678	.501	.031
q2cnew	-.131	.673	.469	-.058
q3cnew	-.089	.564	.361	.063
q4cnew	-.158	.442	.513	-.002
q5cnew	.594	.588	-.511	.192
q6cnew	.593	.588	-.512	.192
q7cnew	.594	.588	-.512	.192
q8cnew	.920	.107	-.056	-.322
q10cnew	.719	.059	-.117	-.441
q11cnew	.920	.107	-.056	-.322
q12cnew	.920	.107	-.056	-.322
q13cnew	.920	.107	-.056	-.322
q14cnew	.975	-.063	.107	.000
q15cnew	.975	-.063	.108	.000
q16cnew	.975	-.063	.108	-.001
q18cnew	.975	-.063	.108	.000
q19cnew	.975	-.063	.108	.000
q20cnew	.975	-.063	.108	.000
q21cnew	.975	-.063	.108	.000
q22cnew	.975	-.063	.108	.000
q23cnew	.926	-.152	.129	.251
q24cnew	.926	-.152	.129	.251
q25cnew	.926	-.152	.128	.251
q26cnew	.926	-.152	.128	.252
q27cnew	.926	-.153	.128	.252

Extraction Method: Principal Component Analysis.  
a. 4 components extracted.

Table 24

**General linear model for satisfaction core questions, with between  
subjects factors gender, children and marital status, and covariates age,  
years sick and educational level**

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.385	1.503(a)	25.000	60.000	.100
	Wilks' Lambda	.615	1.503(a)	25.000	60.000	.100
	Hotelling's Trace	.626	1.503(a)	25.000	60.000	.100
	Roy's Largest Root	.626	1.503(a)	25.000	60.000	.100
age	Pillai's Trace	.365	1.379(a)	25.000	60.000	.155
	Wilks' Lambda	.635	1.379(a)	25.000	60.000	.155
	Hotelling's Trace	.575	1.379(a)	25.000	60.000	.155
	Roy's Largest Root	.575	1.379(a)	25.000	60.000	.155
sick yrs	Pillai's Trace	.224	.692(a)	25.000	60.000	.844
	Wilks' Lambda	.776	.692(a)	25.000	60.000	.844
	Hotelling's Trace	.288	.692(a)	25.000	60.000	.844
	Roy's Largest Root	.288	.692(a)	25.000	60.000	.844
educatio	Pillai's Trace	.291	.987(a)	25.000	60.000	.497
	Wilks' Lambda	.709	.987(a)	25.000	60.000	.497
	Hotelling's Trace	.411	.987(a)	25.000	60.000	.497
	Roy's Largest Root	.411	.987(a)	25.000	60.000	.497
sex	Pillai's Trace	.111	.299(a)	25.000	60.000	.999
	Wilks' Lambda	.889	.299(a)	25.000	60.000	.999
	Hotelling's Trace	.125	.299(a)	25.000	60.000	.999
	Roy's Largest Root	.125	.299(a)	25.000	60.000	.999
children	Pillai's Trace	.290	.979(a)	25.000	60.000	.507
	Wilks' Lambda	.710	.979(a)	25.000	60.000	.507
	Hotelling's Trace	.408	.979(a)	25.000	60.000	.507
	Roy's Largest Root	.408	.979(a)	25.000	60.000	.507
single	Pillai's Trace	.164	.469(a)	25.000	60.000	.980
	Wilks' Lambda	.836	.469(a)	25.000	60.000	.980
	Hotelling's Trace	.195	.469(a)	25.000	60.000	.980
	Roy's Largest Root	.195	.469(a)	25.000	60.000	.980
sex * children	Pillai's Trace	.197	.588(a)	25.000	60.000	.928
	Wilks' Lambda	.803	.588(a)	25.000	60.000	.928
	Hotelling's Trace	.245	.588(a)	25.000	60.000	.928
	Roy's Largest Root	.245	.588(a)	25.000	60.000	.928
sex * single	Pillai's Trace	.228	.708(a)	25.000	60.000	.829
	Wilks' Lambda	.772	.708(a)	25.000	60.000	.829
	Hotelling's Trace	.295	.708(a)	25.000	60.000	.829
	Roy's Largest Root	.295	.708(a)	25.000	60.000	.829
children * single	Pillai's Trace	.275	.912(a)	25.000	60.000	.589

Wilks' Lambda	.725	.912(a)	25.000	60.000	.589
Hotelling's Trace	.380	.912(a)	25.000	60.000	.589
Roy's Largest Root	.380	.912(a)	25.000	60.000	.589
Pillai's Trace	.288	.969(a)	25.000	60.000	.518
Wilks' Lambda	.712	.969(a)	25.000	60.000	.518
Hotelling's Trace	.404	.969(a)	25.000	60.000	.518
Roy's Largest Root	.404	.969(a)	25.000	60.000	.518

a Exact statistic

b Design: Intercept+age+sickys+educatio+sex+children+single+sex \* children+sex \* single+children \* single+sex \* children \* single

**Table 25**

**General linear model for perceived importance core questions, with  
between subjects factors gender, children and marital status, and  
covariates age, years sick and educational level**

**Multivariate Tests(b)**

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.482	2.230(a)	25.000	60.000	.006
	Wilks' Lambda	.518	2.230(a)	25.000	60.000	.006
	Hotelling's Trace	.929	2.230(a)	25.000	60.000	.006
	Roy's Largest Root	.929	2.230(a)	25.000	60.000	.006
age	Pillai's Trace	.221	.679(a)	25.000	60.000	.856
	Wilks' Lambda	.779	.679(a)	25.000	60.000	.856
	Hotelling's Trace	.283	.679(a)	25.000	60.000	.856
	Roy's Largest Root	.283	.679(a)	25.000	60.000	.856
sick yrs	Pillai's Trace	.213	.651(a)	25.000	60.000	.881
	Wilks' Lambda	.787	.651(a)	25.000	60.000	.881
	Hotelling's Trace	.271	.651(a)	25.000	60.000	.881
	Roy's Largest Root	.271	.651(a)	25.000	60.000	.881
educatio	Pillai's Trace	.254	.816(a)	25.000	60.000	.708
	Wilks' Lambda	.746	.816(a)	25.000	60.000	.708
	Hotelling's Trace	.340	.816(a)	25.000	60.000	.708
	Roy's Largest Root	.340	.816(a)	25.000	60.000	.708
sex	Pillai's Trace	.224	.693(a)	25.000	60.000	.843
	Wilks' Lambda	.776	.693(a)	25.000	60.000	.843
	Hotelling's Trace	.289	.693(a)	25.000	60.000	.843
	Roy's Largest Root	.289	.693(a)	25.000	60.000	.843
children	Pillai's Trace	.321	1.136(a)	25.000	60.000	.335
	Wilks' Lambda	.679	1.136(a)	25.000	60.000	.335
	Hotelling's Trace	.473	1.136(a)	25.000	60.000	.335
	Roy's Largest Root	.473	1.136(a)	25.000	60.000	.335
single	Pillai's Trace	.323	1.146(a)	25.000	60.000	.326
	Wilks' Lambda	.677	1.146(a)	25.000	60.000	.326
	Hotelling's Trace	.477	1.146(a)	25.000	60.000	.326
	Roy's Largest Root	.477	1.146(a)	25.000	60.000	.326
sex * children	Pillai's Trace	.176	.513(a)	25.000	60.000	.966
	Wilks' Lambda	.824	.513(a)	25.000	60.000	.966
	Hotelling's Trace	.214	.513(a)	25.000	60.000	.966
	Roy's Largest Root	.214	.513(a)	25.000	60.000	.966
sex * single	Pillai's Trace	.218	.671(a)	25.000	60.000	.864
	Wilks' Lambda	.782	.671(a)	25.000	60.000	.864
	Hotelling's Trace	.279	.671(a)	25.000	60.000	.864
	Roy's Largest Root	.279	.671(a)	25.000	60.000	.864
children * single	Pillai's Trace	.222	.686(a)	25.000	60.000	.850
	Wilks' Lambda	.778	.686(a)	25.000	60.000	.850

Hotelling's Trace	.286	.686(a)	25.000	60.000	.850
Roy's Largest Root	.286	.686(a)	25.000	60.000	.850
Pillai's Trace	.301	1.033(a)	25.000	60.000	.444
Wilks' Lambda	.699	1.033(a)	25.000	60.000	.444
Hotelling's Trace	.430	1.033(a)	25.000	60.000	.444
Roy's Largest Root	.430	1.033(a)	25.000	60.000	.444

a Exact statistic

b Design: Intercept+age+sickyr+s+educatio+sex+children+single+sex \* children+sex \* single+children \* single+sex \* children \* single



**Table 26**  
**General linear model for expectation of change of core questions, with**  
**between subjects factors gender, children and marital status, and**  
**covariates age, years sick and educational level**  
**Multivariate Tests(b)**

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.489	2.259(a)	25.000	59.000	.005
	Wilks' Lambda	.511	2.259(a)	25.000	59.000	.005
	Hotelling's Trace	.957	2.259(a)	25.000	59.000	.005
	Roy's Largest Root	.957	2.259(a)	25.000	59.000	.005
age	Pillai's Trace	.392	1.523(a)	25.000	59.000	.094
	Wilks' Lambda	.608	1.523(a)	25.000	59.000	.094
	Hotelling's Trace	.645	1.523(a)	25.000	59.000	.094
	Roy's Largest Root	.645	1.523(a)	25.000	59.000	.094
sick yrs	Pillai's Trace	.276	.899(a)	25.000	59.000	.605
	Wilks' Lambda	.724	.899(a)	25.000	59.000	.605
	Hotelling's Trace	.381	.899(a)	25.000	59.000	.605
	Roy's Largest Root	.381	.899(a)	25.000	59.000	.605
educatio	Pillai's Trace	.256	.812(a)	25.000	59.000	.712
	Wilks' Lambda	.744	.812(a)	25.000	59.000	.712
	Hotelling's Trace	.344	.812(a)	25.000	59.000	.712
	Roy's Largest Root	.344	.812(a)	25.000	59.000	.712
sex	Pillai's Trace	.203	.602(a)	25.000	59.000	.918
	Wilks' Lambda	.797	.602(a)	25.000	59.000	.918
	Hotelling's Trace	.255	.602(a)	25.000	59.000	.918
	Roy's Largest Root	.255	.602(a)	25.000	59.000	.918
children	Pillai's Trace	.187	.542(a)	25.000	59.000	.953
	Wilks' Lambda	.813	.542(a)	25.000	59.000	.953
	Hotelling's Trace	.230	.542(a)	25.000	59.000	.953
	Roy's Largest Root	.230	.542(a)	25.000	59.000	.953
single	Pillai's Trace	.285	.941(a)	25.000	59.000	.553
	Wilks' Lambda	.715	.941(a)	25.000	59.000	.553
	Hotelling's Trace	.399	.941(a)	25.000	59.000	.553
	Roy's Largest Root	.399	.941(a)	25.000	59.000	.553
sex * children	Pillai's Trace	.201	.593(a)	25.000	59.000	.924
	Wilks' Lambda	.799	.593(a)	25.000	59.000	.924
	Hotelling's Trace	.251	.593(a)	25.000	59.000	.924
	Roy's Largest Root	.251	.593(a)	25.000	59.000	.924
sex * single	Pillai's Trace	.172	.491(a)	25.000	59.000	.974
	Wilks' Lambda	.828	.491(a)	25.000	59.000	.974
	Hotelling's Trace	.208	.491(a)	25.000	59.000	.974
	Roy's Largest Root	.208	.491(a)	25.000	59.000	.974
children * single	Pillai's Trace	.250	.786(a)	25.000	59.000	.743
	Wilks' Lambda	.750	.786(a)	25.000	59.000	.743
	Hotelling's Trace	.333	.786(a)	25.000	59.000	.743

Roy's Largest Root	.333	.786(a)	25.000	59.000	.743
Pillai's Trace	.350	1.268(a)	25.000	59.000	.225
Wilks' Lambda	.650	1.268(a)	25.000	59.000	.225
Hotelling's Trace	.537	1.268(a)	25.000	59.000	.225
Roy's Largest Root	.537	1.268(a)	25.000	59.000	.225

a Exact statistic

b Design: Intercept+age+sickyr+educatio+sex+children+single+sex \* children+sex \* single+children \* single+sex \* children \* single

**Table 27**

**General linear model for satisfaction of disease specific questions, with  
between subjects factors gender, children and marital status, and  
covariates age, years sick and educational level**

**Multivariate Tests(b)**

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.118	2.750(a)	4.000	82.000	.034
	Wilks' Lambda	.882	2.750(a)	4.000	82.000	.034
	Hotelling's Trace	.134	2.750(a)	4.000	82.000	.034
	Roy's Largest Root	.134	2.750(a)	4.000	82.000	.034
age	Pillai's Trace	.053	1.157(a)	4.000	82.000	.336
	Wilks' Lambda	.947	1.157(a)	4.000	82.000	.336
	Hotelling's Trace	.056	1.157(a)	4.000	82.000	.336
	Roy's Largest Root	.056	1.157(a)	4.000	82.000	.336
sick yrs	Pillai's Trace	.077	1.709(a)	4.000	82.000	.156
	Wilks' Lambda	.923	1.709(a)	4.000	82.000	.156
	Hotelling's Trace	.083	1.709(a)	4.000	82.000	.156
	Roy's Largest Root	.083	1.709(a)	4.000	82.000	.156
educatio	Pillai's Trace	.025	.535(a)	4.000	82.000	.711
	Wilks' Lambda	.975	.535(a)	4.000	82.000	.711
	Hotelling's Trace	.026	.535(a)	4.000	82.000	.711
	Roy's Largest Root	.026	.535(a)	4.000	82.000	.711
sex	Pillai's Trace	.028	.594(a)	4.000	82.000	.668
	Wilks' Lambda	.972	.594(a)	4.000	82.000	.668
	Hotelling's Trace	.029	.594(a)	4.000	82.000	.668
	Roy's Largest Root	.029	.594(a)	4.000	82.000	.668
children	Pillai's Trace	.021	.444(a)	4.000	82.000	.777
	Wilks' Lambda	.979	.444(a)	4.000	82.000	.777
	Hotelling's Trace	.022	.444(a)	4.000	82.000	.777
	Roy's Largest Root	.022	.444(a)	4.000	82.000	.777
single	Pillai's Trace	.038	.805(a)	4.000	82.000	.526
	Wilks' Lambda	.962	.805(a)	4.000	82.000	.526
	Hotelling's Trace	.039	.805(a)	4.000	82.000	.526
	Roy's Largest Root	.039	.805(a)	4.000	82.000	.526
sex * children	Pillai's Trace	.067	1.469(a)	4.000	82.000	.219
	Wilks' Lambda	.933	1.469(a)	4.000	82.000	.219
	Hotelling's Trace	.072	1.469(a)	4.000	82.000	.219
	Roy's Largest Root	.072	1.469(a)	4.000	82.000	.219
sex * single	Pillai's Trace	.006	.122(a)	4.000	82.000	.974
	Wilks' Lambda	.994	.122(a)	4.000	82.000	.974
	Hotelling's Trace	.006	.122(a)	4.000	82.000	.974
	Roy's Largest Root	.006	.122(a)	4.000	82.000	.974
children * single	Pillai's Trace	.036	.771(a)	4.000	82.000	.547

sex * children * single	Wilks' Lambda	.964	.771(a)	4.000	82.000	.547
	Hotelling's Trace	.038	.771(a)	4.000	82.000	.547
	Roy's Largest Root	.038	.771(a)	4.000	82.000	.547
	Pillai's Trace					
		.023	.489(a)	4.000	82.000	.744
	Wilks' Lambda	.977	.489(a)	4.000	82.000	.744
	Hotelling's Trace	.024	.489(a)	4.000	82.000	.744
	Roy's Largest Root	.024	.489(a)	4.000	82.000	.744

a Exact statistic

b Design: Intercept+age+sickyr+educatio+sex+children+single+sex \* children+sex \* single+children \* single+sex \* children \* single

**Table 28**

**General linear model for perceived importance of disease  
specific questions, with between subjects factors gender,  
children and marital status, and covariates age, years sick and  
educational level**

**Multivariate Tests(b)**

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.225	5.948(a)	4.000	82.000	.000
	Wilks' Lambda	.775	5.948(a)	4.000	82.000	.000
	Hotelling's Trace	.290	5.948(a)	4.000	82.000	.000
	Roy's Largest Root	.290	5.948(a)	4.000	82.000	.000
age	Pillai's Trace	.041	.880(a)	4.000	82.000	.480
	Wilks' Lambda	.959	.880(a)	4.000	82.000	.480
	Hotelling's Trace	.043	.880(a)	4.000	82.000	.480
	Roy's Largest Root	.043	.880(a)	4.000	82.000	.480
sickys	Pillai's Trace	.064	1.396(a)	4.000	82.000	.243
	Wilks' Lambda	.936	1.396(a)	4.000	82.000	.243
	Hotelling's Trace	.068	1.396(a)	4.000	82.000	.243
	Roy's Largest Root	.068	1.396(a)	4.000	82.000	.243
educatio	Pillai's Trace	.041	.884(a)	4.000	82.000	.477
	Wilks' Lambda	.959	.884(a)	4.000	82.000	.477
	Hotelling's Trace	.043	.884(a)	4.000	82.000	.477
	Roy's Largest Root	.043	.884(a)	4.000	82.000	.477
sex	Pillai's Trace	.058	1.272(a)	4.000	82.000	.288
	Wilks' Lambda	.942	1.272(a)	4.000	82.000	.288
	Hotelling's Trace	.062	1.272(a)	4.000	82.000	.288
	Roy's Largest Root	.062	1.272(a)	4.000	82.000	.288
children	Pillai's Trace	.012	.252(a)	4.000	82.000	.908
	Wilks' Lambda	.988	.252(a)	4.000	82.000	.908
	Hotelling's Trace	.012	.252(a)	4.000	82.000	.908
	Roy's Largest Root	.012	.252(a)	4.000	82.000	.908
single	Pillai's Trace	.021	.448(a)	4.000	82.000	.773
	Wilks' Lambda	.979	.448(a)	4.000	82.000	.773
	Hotelling's Trace	.022	.448(a)	4.000	82.000	.773
	Roy's Largest Root	.022	.448(a)	4.000	82.000	.773
sex * children	Pillai's Trace	.016	.331(a)	4.000	82.000	.856
	Wilks' Lambda	.984	.331(a)	4.000	82.000	.856
	Hotelling's Trace	.016	.331(a)	4.000	82.000	.856
	Roy's Largest Root	.016	.331(a)	4.000	82.000	.856
sex * single	Pillai's Trace	.018	.385(a)	4.000	82.000	.818
	Wilks' Lambda	.982	.385(a)	4.000	82.000	.818
	Hotelling's Trace	.019	.385(a)	4.000	82.000	.818
	Roy's Largest Root	.019	.385(a)	4.000	82.000	.818
Children *	Pillai's Trace	.030	.624(a)	4.000	82.000	.647

single	Wilks' Lambda	.970	.624(a)	4.000	82.000	.647
	Hotelling's Trace	.030	.624(a)	4.000	82.000	.647
	Roy's Largest Root	.030	.624(a)	4.000	82.000	.647
	Pillai's Trace					
sex *						
children *						
single						
	Wilks' Lambda	.938	1.344(a)	4.000	82.000	.261
	Hotelling's Trace	.066	1.344(a)	4.000	82.000	.261
	Roy's Largest Root	.066	1.344(a)	4.000	82.000	.261

a Exact statistic

b Design: Intercept+age+sickys+educatio+sex+children+single+sex \* children+sex \* single+children \* single+sex \* children \* single

Table 29

**General linear model for expectation of change of disease specific questions, with between subjects factors gender, children and marital status, and covariates age, years sick and educational level**

**Multivariate Tests(b)**

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.036	.775(a)	4.000	82.000	.545
	Wilks' Lambda	.964	.775(a)	4.000	82.000	.545
	Hotelling's Trace	.038	.775(a)	4.000	82.000	.545
	Roy's Largest Root	.038	.775(a)	4.000	82.000	.545
Age	Pillai's Trace	.043	.914(a)	4.000	82.000	.460
	Wilks' Lambda	.957	.914(a)	4.000	82.000	.460
	Hotelling's Trace	.045	.914(a)	4.000	82.000	.460
	Roy's Largest Root	.045	.914(a)	4.000	82.000	.460
Sickyr	Pillai's Trace	.139	3.316(a)	4.000	82.000	.014
	Wilks' Lambda	.861	3.316(a)	4.000	82.000	.014
	Hotelling's Trace	.162	3.316(a)	4.000	82.000	.014
	Roy's Largest Root	.162	3.316(a)	4.000	82.000	.014
educatio	Pillai's Trace	.144	3.457(a)	4.000	82.000	.012
	Wilks' Lambda	.856	3.457(a)	4.000	82.000	.012
	Hotelling's Trace	.169	3.457(a)	4.000	82.000	.012
	Roy's Largest Root	.169	3.457(a)	4.000	82.000	.012
Sex	Pillai's Trace	.037	.794(a)	4.000	82.000	.533
	Wilks' Lambda	.963	.794(a)	4.000	82.000	.533
	Hotelling's Trace	.039	.794(a)	4.000	82.000	.533
	Roy's Largest Root	.039	.794(a)	4.000	82.000	.533
Children	Pillai's Trace	.033	.706(a)	4.000	82.000	.590
	Wilks' Lambda	.967	.706(a)	4.000	82.000	.590
	Hotelling's Trace	.034	.706(a)	4.000	82.000	.590
	Roy's Largest Root	.034	.706(a)	4.000	82.000	.590
Single	Pillai's Trace	.016	.336(a)	4.000	82.000	.853
	Wilks' Lambda	.984	.336(a)	4.000	82.000	.853
	Hotelling's Trace	.016	.336(a)	4.000	82.000	.853
	Roy's Largest Root	.016	.336(a)	4.000	82.000	.853
sex * children	Pillai's Trace	.019	.407(a)	4.000	82.000	.803
	Wilks' Lambda	.981	.407(a)	4.000	82.000	.803
	Hotelling's Trace	.020	.407(a)	4.000	82.000	.803
	Roy's Largest Root	.020	.407(a)	4.000	82.000	.803
sex * single	Pillai's Trace	.021	.443(a)	4.000	82.000	.777
	Wilks' Lambda	.979	.443(a)	4.000	82.000	.777
	Hotelling's Trace	.022	.443(a)	4.000	82.000	.777
	Roy's Largest Root	.022	.443(a)	4.000	82.000	.777
Children * single	Pillai's Trace	.079	1.762(a)	4.000	82.000	.145
	Wilks' Lambda	.921	1.762(a)	4.000	82.000	.145
	Hotelling's Trace	.086	1.762(a)	4.000	82.000	.145

sex * children * single	Roy's Largest Root	.086	1.762(a)	4.000	82.000	.145
	Pillai's Trace	.051	1.101(a)	4.000	82.000	.362
	Wilks' Lambda	.949	1.101(a)	4.000	82.000	.362
	Hotelling's Trace	.054	1.101(a)	4.000	82.000	.362
	Roy's Largest Root	.054	1.101(a)	4.000	82.000	.362

a Exact statistic

b Design: Intercept+age+sickyr+educatio+sex+children+single+sex \* children+sex \*  
single+children \* single+sex \* children \* single



**Table 30**

**General linear model for expectation of change of disease specific questions, with between subjects factors gender, children and marital status, and covariates age, years sick and educational level: Tests of Between-Subjects Effects**

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	q27cnew	8.011(a)	10	.801	1.515	.148
	q28cnew	1.409(b)	10	.141	1.319	.233
	q29cnew	5.877(c)	10	.588	2.369	.016
	q30cnew	5.545(d)	10	.554	1.370	.208
Intercept	q27cnew	.408	1	.408	.772	.382
	q28cnew	.118	1	.118	1.105	.296
	q29cnew	.269	1	.269	1.083	.301
	q30cnew	.155	1	.155	.384	.537
age	q27cnew	1.755	1	1.755	3.318	.072
	q28cnew	.007	1	.007	.062	.805
	q29cnew	.077	1	.077	.312	.578
	q30cnew	.024	1	.024	.059	.808
sickysr	q27cnew	.903	1	.903	1.707	.195
	q28cnew	.550	1	.550	5.148	.026
	q29cnew	2.325	1	2.325	9.373	.003
	q30cnew	.009	1	.009	.023	.880
educatio	q27cnew	.676	1	.676	1.278	.261
	q28cnew	.135	1	.135	1.263	.264
	q29cnew	1.569	1	1.569	6.327	.014
	q30cnew	4.013	1	4.013	9.911	.002
sex	q27cnew	.075	1	.075	.142	.707
	q28cnew	.004	1	.004	.034	.854
	q29cnew	.219	1	.219	.884	.350
	q30cnew	.634	1	.634	1.566	.214
children	q27cnew	1.151	1	1.151	2.176	.144
	q28cnew	.037	1	.037	.348	.557
	q29cnew	.041	1	.041	.164	.687
	q30cnew	.069	1	.069	.170	.681
single	q27cnew	.578	1	.578	1.093	.299
	q28cnew	.023	1	.023	.220	.640
	q29cnew	6.11E-005	1	6.11E-005	.000	.988
	q30cnew	.002	1	.002	.004	.952

sex * children	q27cnew	.392	1	.392	.741	.392
	q28cnew	.064	1	.064	.601	.440
	q29cnew	.010	1	.010	.041	.841
	q30cnew	.098	1	.098	.242	.624
sex * single	q27cnew	.014	1	.014	.027	.870
	q28cnew	.167	1	.167	1.566	.214
	q29cnew	.005	1	.005	.020	.888
	q30cnew	.003	1	.003	.007	.932
children * single	q27cnew	1.956	1	1.956	3.698	.058
	q28cnew	.001	1	.001	.006	.939
	q29cnew	.390	1	.390	1.572	.213
	q30cnew	.388	1	.388	.960	.330
sex * children * single	q27cnew	.607	1	.607	1.148	.287
	q28cnew	.005	1	.005	.043	.837
	q29cnew	.616	1	.616	2.482	.119
	q30cnew	.127	1	.127	.313	.578
Error	q27cnew	44.947	85	.529		
	q28cnew	9.080	85	.107		
	q29cnew	21.082	85	.248		
	q30cnew	34.413	85	.405		
Total	q27cnew	58.000	96			
	q28cnew	11.000	96			
	q29cnew	42.000	96			
	q30cnew	62.000	96			
Corrected Total	q27cnew	52.958	95			
	q28cnew	10.490	95			
	q29cnew	26.958	95			
	q30cnew	39.958	95			

a R Squared = .151 (Adjusted R Squared = .051)

b R Squared = .134 (Adjusted R Squared = .033)

c R Squared = .218 (Adjusted R Squared = .126)

d R Squared = .139 (Adjusted R Squared = .037)

## **APPENDIX C**

APRET  
SCRIPT – INSERM  
290 ROUTE DE VIENNE  
69373 LYON CEDEX 08  
April 25, 1995

### **SUBJECTIVE QUALITY OF LIFE PROFILE (SQOLP)**

(To be filled out by the investigator)

Local code # \_\_\_\_\_

Script code # \_\_\_\_\_

(These numbers enable us to compile diverse information about you. However it does not allow us to identify you by name. This questionnaire is confidential and anonymous).

PLEASE INDICATE:

\* The year you were born: 19 \_\_\_\_\_

\* Your sex (check the correct response): \_\_\_\_\_ Male \_\_\_\_\_ Female

\* Today's date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
                    day    month    year

Please reply to each of the following questions by checking the box of the answer that corresponds best to your way of looking at things. Please remember to answer the questions that are on the back of each page.

Not all questions apply to everyone. If a question does not apply to your situation or does not seem relevant, or if you do not know how to answer, or if you do not want to answer the question: please indicate your response in the following manner:

"N" to mean: This question does not apply to me

"?" to mean: I do not know

"R" to mean: I refuse to answer

1. Concerning your physical abilities (or difficulties) to perform the movements you usually do every day (lifting objects, bending over, dressing yourself, washing, climbing stairs),

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

2. Concerning your abilities (or difficulties) to go out or move about outside the house,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

3. Concerning your overall fitness, that is you get tired more or less easily,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

**In your life you consider this to be:**

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

**You expect in the coming months that this will:**

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

**4. Concerning how you feel physically (pain for example),**

**You are:**

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

**In your life you consider this to be:**

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

**You expect in the coming months that this will:**

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

**5. Concerning your relationships with other people,**

**You are:**

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied

- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

6. Concerning your sleep,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

7. Concerning your abilities (or difficulties) to think or focus your attention,

**You are:**

- ☐ **Very dissatisfied**
- ☐ **Somewhat dissatisfied**
- ☐ **Somewhat satisfied**
- ☐ **Very satisfied**
- ☐ **Indifferent (either satisfied nor dissatisfied)**

**In your life you consider this to be:**

- ☐ **Unimportant**
- ☐ **Somewhat important**
- ☐ **Very important**
- ☐ **Extremely important**

**You expect in the coming months that this will:**

- ☐ **Change much for the worse**
- ☐ **Change somewhat for the worse**
- ☐ **Not change**
- ☐ **Change somewhat for the better**
- ☐ **Change much for the better**

**8. Concerning your sexuality,**

**You are:**

- ☐ **Very dissatisfied**
- ☐ **Somewhat dissatisfied**
- ☐ **Somewhat satisfied**
- ☐ **Very satisfied**
- ☐ **Indifferent (either satisfied nor dissatisfied)**

**In your life you consider this to be:**

- ☐ **Unimportant**
- ☐ **Somewhat important**
- ☐ **Very important**
- ☐ **Extremely important**

**You expect in the coming months that this will:**

- ☐ **Change much for the worse**
- ☐ **Change somewhat for the worse**
- ☐ **Not change**
- ☐ **Change somewhat for the better**
- ☐ **Change much for the better**

9. Concerning people's attitudes toward you,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

10. Concerning your meals, what you can eat, or your food,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better



- ☐ Change much for the better

11. Concerning the free time that you have (or do not have),

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

12. Concerning your income or the money that you have available to you,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse

- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

13. Concerning the time you spend (or do not spend) with friends,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

14. Concerning the fact that you have (or not have) a professional activity,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

**You expect in the coming months that this will:**

- ☐ **Change much for the worse**
- ☐ **Change somewhat for the worse**
- ☐ **Not change**
- ☐ **Change somewhat for the better**
- ☐ **Change much for the better**

**15. Concerning how you feel about yourself,**

**You are:**

- ☐ **Very dissatisfied**
- ☐ **Somewhat dissatisfied**
- ☐ **Somewhat satisfied**
- ☐ **Very satisfied**
- ☐ **Indifferent (either satisfied nor dissatisfied)**

**In your life you consider this to be:**

- ☐ **Unimportant**
- ☐ **Somewhat important**
- ☐ **Very important**
- ☐ **Extremely important**

**You expect in the coming months that this will:**

- ☐ **Change much for the worse**
- ☐ **Change somewhat for the worse**
- ☐ **Not change**
- ☐ **Change somewhat for the better**
- ☐ **Change much for the better**

**16. Concerning your personal or inner life (for example: reflexion, reading, medication, daydreaming),**

**You are:**

- ☐ **Very dissatisfied**
- ☐ **Somewhat dissatisfied**
- ☐ **Somewhat satisfied**
- ☐ **Very satisfied**
- ☐ **Indifferent (either satisfied nor dissatisfied)**

**In your life you consider this to be:**

- ☐ **Unimportant**
- ☐ **Somewhat important**

- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

17. Concerning your physical health,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

18. Concerning the fact that you have (or do not have) relationships with close family or friends,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

**You expect in the coming months that this will:**

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

**19. Concerning the fact that you have (or do not have) personal activities or leisure (for example: movies, concerts, sports, vacations, do-it-yourself, cultural or artistic activities...),**

**You are:**

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

**In your life you consider this to be:**

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

**You expect in the coming months that this will:**

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

**20. Concerning the fact that you participate (or do not participate) in group activities (for example: cultural, union, religious...),**

**You are:**

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied

- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant  
☐ Somewhat important  
☐ Very important  
☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse  
☐ Change somewhat for the worse  
☐ Not change  
☐ Change somewhat for the better  
☐ Change much for the better

21. Concerning the fact that you live (or do not live) with someone (for example: as a couple, as a family, as a single person...),

You are:

- ☐ Very dissatisfied  
☐ Somewhat dissatisfied  
☐ Somewhat satisfied  
☐ Very satisfied  
☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant  
☐ Somewhat important  
☐ Very important  
☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse  
☐ Change somewhat for the worse  
☐ Not change  
☐ Change somewhat for the better  
☐ Change much for the better

22. Concerning the material conditions of your daily life,

You are:

- ☐ Very dissatisfied

- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

**23. Concerning your physical abilities,**

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

**24. Concerning the fact that you feel (or do not feel) free,**

**You are:**

- ☐ **Very dissatisfied**
- ☐ **Somewhat dissatisfied**
- ☐ **Somewhat satisfied**
- ☐ **Very satisfied**
- ☐ **Indifferent (either satisfied nor dissatisfied)**

**In your life you consider this to be:**

- ☐ **Unimportant**
- ☐ **Somewhat important**
- ☐ **Very important**
- ☐ **Extremely important**

**You expect in the coming months that this will:**

- ☐ **Change much for the worse**
- ☐ **Change somewhat for the worse**
- ☐ **Not change**
- ☐ **Change somewhat for the better**
- ☐ **Change much for the better**

**25. Concerning the way you see your future,**

**You are:**

- ☐ **Very dissatisfied**
- ☐ **Somewhat dissatisfied**
- ☐ **Somewhat satisfied**
- ☐ **Very satisfied**
- ☐ **Indifferent (either satisfied nor dissatisfied)**

**In your life you consider this to be:**

- ☐ **Unimportant**
- ☐ **Somewhat important**
- ☐ **Very important**
- ☐ **Extremely important**

**You expect in the coming months that this will:**

- ☐ **Change much for the worse**
- ☐ **Change somewhat for the worse**
- ☐ **Not change**
- ☐ **Change somewhat for the better**
- ☐ **Change much for the better**



**26. Concerning the fact that you have (or do not have) a religious faith,**

**You are:**

- ☐ **Very dissatisfied**
- ☐ **Somewhat dissatisfied**
- ☐ **Somewhat satisfied**
- ☐ **Very satisfied**
- ☐ **Indifferent (either satisfied nor dissatisfied)**

**In your life you consider this to be:**

- ☐ **Unimportant**
- ☐ **Somewhat important**
- ☐ **Very important**
- ☐ **Extremely important**

**You expect in the coming months that this will:**

- ☐ **Change much for the worse**
- ☐ **Change somewhat for the worse**
- ☐ **Not change**
- ☐ **Change somewhat for the better**
- ☐ **Change much for the better**

**27. Concerning what is happening in the world (for example: economic, social, political...),**

**You are:**

- ☐ **Very dissatisfied**
- ☐ **Somewhat dissatisfied**
- ☐ **Somewhat satisfied**
- ☐ **Very satisfied**
- ☐ **Indifferent (either satisfied nor dissatisfied)**

**In your life you consider this to be:**

- ☐ **Unimportant**
- ☐ **Somewhat important**
- ☐ **Very important**
- ☐ **Extremely important**

**You expect in the coming months that this will:**

- ☐ **Change much for the worse**

- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

28. Concerning your relationship with alcohol,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

29. Concerning your relationship to drugs,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

30. Concerning your attitude about taking medications,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

Thank you for your participation.

All rights for duplication, especially translation, modification and reproduction by any means are reserved – APRET worldwide.

### **SQOLP QUESTIONNAIRE: CORE**

Concerning:

1. Your physical abilities (or difficulties) to perform the movements you usually do every day (lifting objects, bending over, dressing yourself, washing, climbing stairs),
2. Your abilities (or difficulties) to go out or move about outside the house,
3. Your overall fitness, that is you get tired more or less easily,
4. How you feel physically (pain for example),
5. Your relationships with other people,
6. Your sleep,

7. Your abilities (or difficulties) to think or focus your attention,
8. Your sexuality,
9. People's attitudes toward you,
10. Your meals, what you can eat, or your food,
11. The free time that you have (or do not have),
12. Your income or the money that you have available to you,
13. The time you spend (or do not spend) with friends,
14. The fact that you have (or not have) a professional activity,
15. How you feel about yourself,
16. Your personal or inner life (for example: reflexion, reading, medication, daydreaming),
17. Your physical health,
18. The fact that you have (or do not have) relationships with close family or friends,
19. The fact that you have (or do not have) personal activities or leisure (for example: movies, concerts, sports, vacations, do-it-yourself, cultural or artistic activities...),
20. The fact that you participate (or do not participate) in group activities (for example: cultural, union, religious...),
21. The fact that you live (or do not live) with someone (for example: as a couple, as a family, as a single person...),
22. The material conditions of your daily life,
23. Your physical abilities,
24. The fact that you feel (or do not feel) free,
25. The way you see your future,
26. The fact that you have (or do not have) a religious faith,
27. What is happening in the world

### **MEASURES**

#### **You are:**

Very dissatisfied

Somewhat dissatisfied  
worse

Indifferent (neither satisfied  
nor dissatisfied)  
better

Somewhat satisfied

#### **You consider this to be:**

Unimportant

Somewhat important

Very important

Extremely important

#### **You expect to be:**

Change much for the worse

Change somewhat for the

Not change

Change somewhat for the

Change much for the better

### **SUBJECTIVE QUALITY OF LIFE PROFILE QUESTIONNAIRE (PQVS)**

The aim of this questionnaire is to explore the principal domains of life, these being:

1. functional life,
2. social life
3. material life,
4. spiritual life.

To cover these four domains, the (PQVS) is organized into two levels:

- the measurements (the question)
- the items (the domain covered by the question)

It comprises:

- on the one hand, a section consisting of the CORE QUESTIONNAIRE, that is the unavoidable questions and the items which will be used in most applications,

- on the other hand, an OPTIONAL SECTION, containing other questions and proposing other items for particular populations or specific diseases.

The measurements concern:

- performance (or change),
- satisfaction,
- the importance attached,
- the change expected,
- coping

THE MEASUREMENT OF SATISFACTION IS PRESENT IN ALL THE QUESTIONNAIRES: with reference to the domain explored by the item if it is the questionnaire at the beginning of the study or with reference to change for this item if it is the questionnaire at the conclusion of the study. The other measurements are optional.

As for the phrasing of the questions, we would draw attention to the fact that it should not be normative nor suggest that certain life styles are better than others. For example, people should not be asked if they are happy with their marriage, which implies that they should be married. Rather they should be asked if they are happy living as a couple or single.

### **THE QUESTIONS INCLUDED IN THE CORE OF THE QUESTIONNAIRE**

Beginning questionnaire:

Concerning ... you feel:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

Follow-up questionnaire:

Concerning the change (or lack of change) since... you are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (either satisfied nor dissatisfied)

### **THE ITEMS INCLUDED IN THE CORE OF THE QUESTIONNAIRE**

1. Your physical ability to perform everyday movements (i.e. lifting objects, bending over, dressing yourself, washing, climbing stairs, etc.):
2. Your ability to get out and about outside the home:
3. Your overall fitness, ~~during the day~~, do you feel tired:
4. Feeling (or not feeling) aches and/or pains in some part of your body:
5. Your relationship with other people in general:
6. The way you sleep:
7. Your ability to think and concentrate:
8. Your sexual life;
9. Other people's attitudes towards you,
10. Your food, what you can (or cannot) eat:
11. The fact that you have (or do not have) free time:
12. Your income; the money that you have at your disposal:
13. The time you spend (or do not spend) with friends:
14. The fact that you have (or not have) a professional activity:
15. With regard to yourself opinion:
16. Your inner life (reflecting, reading, medication):
17. Your health status;
18. With regard to the relationships that you have (or do not have) with your family:
19. With regard to any hobbies or activities that you might have (for example: sport, do-it-yourself, painting):
20. With regard to your participation (or not) in various activities (cultural, religious, trade unions):
21. Living (or not) with someone:
22. Your material conditions of your day to day life:
23. Your physical capacities:
24. The fact that you feel free or not:
25. The way you see your future,
26. With regard to any religious convictions that you may (or may not) have:
27. With regard to what is going on in the world (economically, socially, politically):

### **THE QUESTIONS**

With reference to...

You feel things are going:

- very badly
- fairly badly
- neither well nor bad
- fairly well
- very well

**In this respect you are:**

- very dissatisfied
- fairly dissatisfied
- indifferent
- fairly satisfied
- very satisfied

**In your life this plays:**

- an insignificant part
- a fairly important part
- a very important part
- an extremely important part

**In the coming months, you expect that this will:**

- change much for the worse
- change rather for the worse
- not change
- change rather for the better
- change much for the better

**You feel that, since... , this has:**

- changed much for the worse
- changed rather for the worse
- not changed
- changed rather for the better
- changed much for the better

**With reference to the change (or lack of the change) since... , you are:**

- very dissatisfied
- fairly dissatisfied
- indifferent
- fairly satisfied
- very satisfied

**In this domain, you manage to face up to possible difficulties:**

- very badly
- fairly badly
- neither well nor bad
- fairly well
- very well

What you are living through is:

- very far from what you would like
- far from what you would like
- fairly far from what you would like
- fairly close to what you would like
- close to what you would like
- very close to what you would like

You experience it as being:

- very painful and hard to bear
- painful and hard to bear
- fairly painful and hard to bear
- neither painful nor hard to bear
- fairly satisfying and pleasant
- satisfying and pleasant
- very satisfying and pleasant